

# Agenda-Setting for Global Public Health: The Need for a Horizontal Perspective in the Public and Political Arenas

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Undergraduate Honors Program

International Studies

**Agenda-Setting for Global Public Health: The Need for a  
Horizontal Perspective in the Public and Political Arenas**

by

**Jennifer Close**

submitted in partial fulfillment of the requirements  
the degree of

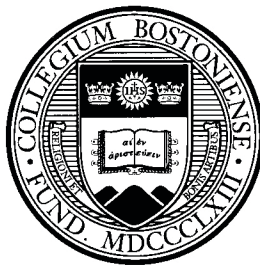
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### **Abstract**

Public health is of critical importance in the world today, and particularly in the South, where developing states, unable to provide for the health of their citizens, continue to carry the global burden of disease. There is more funding available to global health than ever before. If these assets are going to be effective in advancing the health of the developing world, then they must be directed towards comprehensive measures that address the needs of entire populations, rather than disease-specific programs which do little to confront the challenges facing the world's poor. The latter approach may be dominating the field of public health, but horizontal, capacity-building programs can become the norm in this arena. In order to transform the global health-giving infrastructure, the public and political agendas in the United States and every other donor country must be reset. By transposing the tactics employed by activists of the most successful health campaign in history—that of the HIV/AIDS pandemic—onto the global health movement, proponents of this approach can position it on the agendas of states throughout the world, and construct sustainable healthcare systems that will attend to the plight of the current generation, as well as provide for the well-being of those to come.



AGENDA-SETTING FOR GLOBAL PUBLIC HEALTH:

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by

Jennifer Close

Submitted in partial fulfillment

of graduation requirements for the degree of

Bachelor of Arts

Boston College

International Studies Program

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## **Abstract**

Public health is of critical importance in the world today, and particularly in the South, where developing states, unable to provide for the health of their citizens, continue to carry the global burden of disease. There is more funding available to global health than ever before. If these assets are going to be effective in advancing the health of the developing world, then they must be directed towards comprehensive measures that address the needs of entire populations, rather than disease-specific programs which do little to confront the challenges facing the world's poor. The latter approach may be dominating the field of public health, but horizontal, capacity-building programs can become the norm in this arena. In order to transform the global health-giving infrastructure, the public and political agendas in the United States and every other donor country must be reset. By transposing the tactics employed by activists of the most successful health campaign in history—that of the HIV/AIDS pandemic—onto the global health movement, proponents of this approach can position it on the agendas of states throughout the world, and construct sustainable healthcare systems that will attend to the plight of the current generation, as well as provide for the well-being of those to come.

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I want to begin by thanking my family, and particularly my grandparents. I would never have written this thesis if not for your love and support. Each of you—Dad, Lauren, Nana, and Pop—has influenced my formation as a student, and more importantly, as a person. I am so grateful to have you all in my life.

I would also like to thank my thesis advisor, Father James Keenan, for your patience, guidance, and invaluable insight. Your constant encouragement and unfailing interest in my topic was critical to the completion of this work.

Lastly, I want to recognize all of the men and women in the developing world that are suffering from a lack of basic healthcare. In my own small way, I hope that this thesis is an acknowledgement of your plight, even if it is not a solution to the enormous challenges facing the global health infrastructure.

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## CHAPTER ONE: INTRODUCTION

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### Overview

Interest in global health is at an unprecedented level. Never before in history has international public health received so much attention, funding, and resources. In response to the potency of globalization and the emergence of high profile diseases such as the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), billions of dollars are being donated by governments, public and private organizations, philanthropists, celebrities, and individuals to improve health conditions throughout the world. Despite this extraordinary increase in giving to global health, it has become apparent that more health spending does not necessitate more effective or equitable healthcare in the developing world. While garnering funds is necessary to improve global health, the resources that are available need to be allocated more efficiently. More money is not enough.<sup>1</sup> Until global health funding is distributed more judiciously, men and women will die from preventable diseases, maternal and infant care will flounder, and developing states will remain trapped in a cycle of poverty that is both caused and perpetuated by their failing public health systems. The time for addressing the challenges of global health is now, and we must reevaluate the way in which we attend to these problems if we are to capitalize on the resources currently at hand.

Global health initiatives have traditionally been guided by two parallel approaches, both of which are determined to control infectious diseases and improve health for the world's poor: Vertical, disease-specific programs, and horizontal, capacity-

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<sup>1</sup> William C. Hsiao, "Why Is A Systemic View Of Health Financing Necessary?," *Health Affairs* 26, no. 4 (2007): 950-51.

building strategies.<sup>2</sup> The international health system is currently driven by the former, selective approach. A product of the focus on HIV/AIDS, and to a lesser extent, tuberculosis and malaria, the verticalization of funding has become the norm in the global health-giving infrastructure. These initiatives are characterized by their independence from the rest of the healthcare system and their focus on a single, notorious disease. Proponents of this strategy argue that its merit lies in its ability to elicit funds, mobilize support, encourage action, and obtain results quickly. Nevertheless, critics maintain that these programs are short-term solutions that contribute to local brain drain, the fragmentation of public health systems, the neglect of other diseases, and donor fatigue. Furthermore, it is often noted that the vertical approach to global health is creating a mismatch between the preferences of donors and the needs of recipient states; this imbalance has yet to be reconciled.

Targeted spending policies are countered by the horizontal approach to global health. This alternative is one that many believe could resolve the supply-and-demand problem presented by the verticalization of funding. This comprehensive framework emphasizes the provision of basic needs, and the construction and promotion of health infrastructures in the developing world. Those who question the potential of this strategy contend that it is unable to marshal sufficient support and funding, and while it is important to strengthen healthcare systems in developing states, the burden of disease in these countries is overwhelming and must be addressed without delay.

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<sup>2</sup> Darrell Tan, Ross Upshur, and Nathan Ford, "Global Plagues and the Global Fund: Challenges in the Fight Against HIV, TB, and Malaria," *BMC International Health and Human Rights* (April 1, 2003), <http://www.biomedcentral.com/1472-698X/3/2>.

These strategies have been debated constantly in recent years: Nowhere is this dispute more apparent than in Laurie Garrett's "The Challenge of Global Health," and the heated responses it has elicited from such renowned scholars as Jeffrey Sachs, Alex de Waal, and Paul Farmer. This controversy has remained a dichotomy, with individuals actively supporting either targeted or comprehensive approaches to global health, but not both. However, a new framework for understanding this field, one that reconciles these strategies, has been proposed. Some scholars now argue that these means are not mutually exclusive, and not only can they work side by side, but that the future of global health depends on them complementing one another. If specific diseases are to be countered and effectively controlled, then they must be addressed by thriving healthcare systems.

While the promotion of public health infrastructures seems to be the most powerful method of improving global health and allocating scarce resources more efficiently, advocates of this approach have been pessimistic over their ability to bridge theory and practice. It is extremely challenging to convince donor states and their populations to fund broad-based health measures rather than specific projects such as HIV/AIDS programs or child immunizations.<sup>3</sup> Few scholars have proposed a method for raising capital and resources to support horizontal endeavors in a system powered by the popularity of high profile diseases and targeted spending.

The supply-and-demand challenge presented by this structure is not one that will be resolved quickly. This problem is one of agenda-setting; targeted spending policies

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<sup>3</sup> George J. Schieber et al., "Financing Global Health: Mission Unaccomplished," *Health Affairs* 26, no. 4 (2007): 924-25.

have been popularized and embedded in donor states and will not be easily displaced. These approaches have been framed in such a way that they appear to be the most critical in the developing world. If society is to progress from the contemporary model of global health giving to a more comprehensive strategy, then both the public and political agendas in the United States and other donor countries need to change. There must be a shift in the way these nations understand giving; the story of what really works to improve global health needs a new chapter.

The HIV/AIDS pandemic, which was identified just three decades ago, represents an exceptional case in the history of health and disease. Since its discovery in 1981, it has generated an unprecedented amount of funding and attention, and has propelled itself and other infectious illnesses onto the public and political agendas. This disease, the largest public health emergency in the world, is that which initiated the surge in donations to global health and sparked international interest in the issues surrounding it.<sup>4</sup> The extraordinary response to this pandemic can be attributed to the efforts of AIDS activists who catered to the humanitarian concerns of the public, focused attention on the relevance of this disease to domestic health, and contextualized HIV/AIDS as a threat to international security.<sup>5</sup>

The lessons learned from the HIV/AIDS campaign in the United States can be adapted and applied to other health issues. This thesis will focus on the process of

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<sup>4</sup> Laurie Garrett, "Midway in the Journey," *Foreign Affairs* (January 24, 2007), [http://www.foreignaffairs.org/special/global\\_health/garrett](http://www.foreignaffairs.org/special/global_health/garrett).

<sup>5</sup> Gregory K. Folkers and Anthony S. Fauci, "The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance," *The Journal of the American Medical Association* 286, no. 4 (2001): 460-61.

agenda-setting for HIV/AIDS, and demonstrate that a broad-based interest in global health can be initiated by competent and careful framing.

### **Argument**

My argument is simple. Proponents of a comprehensive approach to global health can successfully place broad-based programs on the American public and political agendas by adopting the strategies utilized by early AIDS activists. These men and women mobilized interest in HIV/AIDS and generated funding for this disease by appealing to the humanitarian impulses of citizens, and framing this disease as a threat to domestic and international security.<sup>6</sup>

By drawing upon the moral concern raised by the idea of health as a global public good—an inclusive entity that everyone should enjoy and contribute towards if possible, the implications of globalization for the transmission of disease from the developing world to the United States, and the effects of poor health in the South on the political, economic, and physical health of America, concern and interest in integrated health initiatives can be galvanized.<sup>7</sup> Lessons on agenda-setting, learned from the most successful health campaign in history—that of the HIV/AIDS pandemic—can be transposed onto the international public health movement in order to affect the lives of millions of men and women in the developing world. In this way, horizontal approaches can become the primary health strategy in the international community and prevent the verticalization of funding from suppressing the provision of basic care, contributing to

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<sup>6</sup> Folkers and Fauci, “The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance,” 460-61.

<sup>7</sup> Inge Kaul and Michael Faust, “Global public goods and health: taking the agenda forward,” *Bulletin of the World Health Organization* 79, no. 9 (2001): 869.

brain drain, perverting health budgets, and overwhelming weak health infrastructures in low- and middle-income countries. Reframing broad-based measures will place them on the international agenda, amass funds to be used towards them, and enact them in the developing world.

The introduction of horizontal, capacity-building strategies is essential to the health of men and women in the global South. This method creates sustainable health infrastructures that address the needs of entire populations, both those who are infected with a specific disease and those who are not, provides a structure within which targeted programs can flourish, aligns donor priorities and local needs, and contributes to maternal survival and overall life expectancy. Global health issues are situated at the threshold of life and death; millions of lives are at stake. The approach taken by the majority of global health programs may seem of little significance to those in the developed world, but to those in underdeveloped nations, this decision represents the difference between basic healthcare and expiration.

Lives are not the only matter hanging in the balance. Billions of dollars are being donated towards the improvement of health for individuals in the developing world; these dollars are not being spent effectively. While the intentions behind them are admirable, their actual use is grounded in misguided priorities. Horizontal approaches should not be allowed to fall into the darkroom of good ideas gone awry for fear of them being too bland to garner resources. Broad-based, comprehensive measures can be framed in terms of humanitarian and security concerns and consequently, be placed on the public and political agendas in the US and every other state.

## **The Research Design**

The HIV/AIDS campaign was extremely successful in placing both itself, and global health, onto the international agenda. Accordingly, it seems that an examination of the conditions under which it was able to achieve this is not only relevant, but also necessary.<sup>8</sup> This thesis makes two arguments. First, AIDS activists in the United States innovated the classic approach to agenda-setting in order to position this disease on the public and political agendas, and change society's perception of it. The lessons learned from this movement can be used to reframe horizontal approaches to global health, compel them onto the American agendas, and redeem global healthcare initiatives in developing states.

This thesis will focus on the efforts of AIDS activists in the US and the positioning of integrated measures onto the American agendas for several reasons. To begin with, it was the efforts of activists in this country that revolutionized the public's perception of this disease; HIV/AIDS was not an issue until these men and women made it one. Furthermore, if comprehensive, broad-based measures can garner the attention of the American people and their government, then this state's influence will be sufficient to affect the programs of donor states throughout the world.

Chapter Three of this thesis provides an in-depth explanation of agenda-setting and policy formation. It will investigate how issues are placed on the public and political agendas and once there, how conceptions of these stories are manipulated, and strategies to address them created. These phenomena will be depicted as a product of the

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<sup>8</sup> Kenneth R. Rutherford, "The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines," *World Politics* 53, no. 1 (October 2000): 76.



composition of causal narratives, active participants, and processes by which agenda items and their alternatives reach the point of affecting real change.<sup>910</sup>

The magnitude and rapidity with which HIV/AIDS came to dominate the American agendas and subsequently, those of a number of other countries, are two of the reasons why I will be using this disease as my case-study. By illustrating how this infectious illness, which was identified only thirty years ago, and which has come to be recognized as that which spurred the entire global health movement, came to be placed on these agendas, I am confident that the hallmarks of its approach can be superimposed onto horizontal initiatives and impel their transition from obscure and impoverished to well-known and subsidized.

### **A Roadmap of This Thesis**

A brief report on the current state of global health will begin Chapter Two of this thesis. The bulk of this section will, however, focus on the controversy between targeted spending and comprehensive measures in healthcraft. It will touch upon the advantages and disadvantages of each approach, why many scholars believe vertical initiatives are dominating the global health arena, and why various academics have come to accept that health would be best served by a synthesis of these strategies.

Chapter Three outlines the principal theories of agenda-setting and examines their relevance, strengths, and weaknesses with regards to contemporary problems and policies. It will also review the reasons why I chose HIV/AIDS as my case-study. This

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<sup>9</sup> Deborah A. Stone, "Causal Stories and the Formation of Policy Agendas," *Political Science Quarterly* 104, no. 2 (1989): 281.

<sup>10</sup> John W. Kingdon, *Agendas, Alternatives, and Public Policies* (New York, NY: HarperCollins College Publishers, 1995), 253.

chapter, which is strictly theoretical, will lay the foundation from which the techniques employed by HIV/AIDS activists can be studied, as well as determine whether this campaign was exceptionally lucky or exceptionally innovative.

Chapter Four analyzes the positioning of HIV/AIDS on the American public agenda. After first highlighting the critical actors, events, and policies in the history of this disease, I will utilize the principles presented in Chapter Three to address how AIDS activists were able to place this disease on the American agenda and revolutionize the public's perception of it.

Likewise, Chapter Five explores the manner in which HIV/AIDS was positioned on the American political agenda. By studying the evolution of this disease from that which was ignored by politicians, to that which has become the primary health concern in Washington, we can learn what techniques to apply to the global public health campaign to successfully place it on the agendas of the world's most powerful states.

Chapter Six will discuss the actions activists can take to reset agendas in states throughout the world with international public health, and transform the global health giving infrastructure from one beset with problems caused by its insistence on the verticalization of funding, to one centered on capacity-building strategies and supplemented by disease-specific initiatives. In this way, millions of lives will be saved, and improvements in health will act as the catalysts that spark development in the world's most impoverished states.

## CHAPTER TWO: THE CURRENT CONTROVERSY

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### The State of Global Health

In terms of technology, prevention, and treatment, healthcare has made remarkable progress in recent years. A product of scientific achievement, the information revolution, and economic globalization, this field has improved markedly. Men and women can live longer, have transformative medical and cosmetic surgeries, and stave off illnesses that were once considered fatal. These advancements, however, are neither universally accessible, nor even known to the vast majority of humankind. International inequality relative to health and wealth is increasing, and the world's poor have been unable to benefit from the tremendous accomplishments of their own kind.<sup>1</sup> Though overall life expectancies are rising, indices of health are actually worsening in much of the developing world, and particularly sub-Saharan Africa.<sup>2</sup> The glitter and excitement of life-saving therapies, revolutionary pharmaceuticals, and reproductive technologies are blinding the world's wealthy to disturbing local and regional reversals in the global South.<sup>3</sup>

The burden of disease is progressively heavier in the developing world, where citizens suffer from infections, chronic illnesses, malnutrition and poor reproductive health. The top three killers in many of these impoverished states are those which developed nations began to treat long ago: Maternal death surrounding childbirth, and

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<sup>1</sup> Solomon R. Benatar, Abdallah S. Daar, and Peter A. Singer, "Global health ethics: the rationale for mutual caring," *International Affairs* 79, no. 1 (2003): 107.

<sup>2</sup> David Banta, "Economic Development Key to Healthier World," *The Journal of the American Medical Association* 287, no. 24 (2002): 3195.

<sup>3</sup> Laurie Garrett, *Betrayal of Trust: The Collapse of Global Public Health* (New York, NY: Hyperion, 2000), 547.

pediatric respiratory and intestinal infections stemming from pulmonary failure or uncontrolled diarrhea.<sup>4</sup> These preventable deaths are not the only health problems wreaking havoc in these countries. Infectious diseases are proliferating and dispersing, both those that are familiar and those that are relatively obscure; from malaria to the Nipah virus, the health of billions of men and women is being compromised. Drug-resistant strains of tuberculosis are emerging, the human immunodeficiency virus—with which 33.2 million people already live—claims new victims everyday, and severe acute respiratory syndrome and avian influenza pose threats to our species as least as great as that of the bubonic plague.<sup>5</sup> In spite of a growing volume of knowledge on how to aid the human body, individuals are as vulnerable to infectious diseases, microbial resistance, and death as ever before.

Once contained largely in the developing world, these illnesses are now traversing national borders. A consequence of globalization, ill health in any population affects that of every other. People and goods are no longer the only entities moving from one state to another; microbes do not recognize socioeconomic status, skin color, nationality, or physical boundaries. It was the gradual awareness of this fact, sparked by the HIV/AIDS pandemic nearly three decades ago, that roused the developed world's consciousness to the realities of global health and its ubiquitous effects for every human being. This newfound appreciation for the linkages between mankind led to a dramatic increase in global health giving; whereas there was once a dearth of resources for this field, more

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<sup>4</sup> Laurie Garrett, "The Challenge of Global Health," *Foreign Affairs* 86, no. 1 (2007): 19.

<sup>5</sup> UNAIDS, "UNAIDS Fact Sheet, Revised HIV estimates," UNAIDS, [http://data.unaids.org/pub/EPISlides/2007/07118\\_epi\\_revisions\\_factsheet\\_en.pdf](http://data.unaids.org/pub/EPISlides/2007/07118_epi_revisions_factsheet_en.pdf) (accessed December 7, 2007).

money is being donated towards the improvement of health for the world's poor than ever before.

Humanitarian concern and enlightened self-interest have caused donor funding to rise steadily over the last two decades, and double since 2000, culminating in a total global health expenditure of \$14 billion US dollars in 2004.<sup>6</sup> (USD) Although more money is needed to combat the sea of illness and disease plaguing the world's destitute citizens, this influx of monetary flows is indicative of progress; global health is finally a priority for donors everywhere. This is further evidenced by the establishment of the Bill and Melinda Gates Foundation—which has given away \$6.6 billion USD since its inception six years ago, the formation of the US President's Emergency Plan for AIDS Relief (PEPFAR), and the creation of the Global Fund to Fight AIDS, Tuberculosis, and Malaria. It is also witnessed in the birth of an army of non-governmental organizations (NGO) dedicated to global health, increases in donations from member states of the Organization for International Cooperation and Development, and a surge of interest and funding from international financial institutions including the World Bank.<sup>7</sup> With wealth comes responsibility, and now that the world has finally stood up and taken notice of global health, she must rise to the challenge of improving it.

### **The Present Debate**

How can funds dedicated towards global health be best spent? How can they be used most effectively, in order so that the benefits in terms of human lives saved are

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<sup>6</sup> Jennifer Kates, "Global health funding: a glass half full?," *The Lancet* 368, no. 9531 (2006): 1.

<sup>7</sup> Garrett, "The Challenge of Global Health," 16-17.

maximized? The profusion of responses that these questions have elicited has prompted what is arguably the most significant debate in the sphere of global health: horizontal versus vertical spending. The former is characterized by integrated, multisectoral approaches to the improvement of health that encourage capacity-strengthening, institution building, and local ownership.<sup>8</sup> With an emphasis on development and sustainability, horizontal initiatives fortify health infrastructures and provide for the basic health needs of individuals. Alternatively, vertical programs are top-down, interventionist, and target specific diseases and illnesses. These approaches are not assimilated into the larger health infrastructures of states and generally focus on curative medicine. This contentious debate is a live one in society and draws forth powerful emotions from supporters and opponents on either side. But, with billions of dollars at stake, and billions of lives hanging in the balance, it is imperative that this dispute reaches a conclusion. Before one can understand the nature of the contemporary discourse on this subject and assess its future, however, one must first be familiar with the roots of this controversy, born from a conference held nearly thirty years ago.

The genesis of this conflict is the signing of the Declaration of Alma Ata in September of 1978 at the International Conference on Primary Health Care in Alma Ata, Kazakhstan. At this meeting, the world's health ministers and experts declared primary health care (PHC) as the strategy that would guide all future global health endeavors. A response to the short-term and relatively ineffective disease-specific interventions of the 1950s and 1960s, the idea of primary healthcare, as introduced by the World Health

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<sup>8</sup> Annette Flanagan and Margaret Winker, "Global Health - Targeting Problems and Achieving Solutions: A Call for Papers," *The Journal of the American Medical Association* 290, no. 10 (2003): 1382-83.

Organization (WHO) and the United Nations Children's Fund, is embodied by the phrase, "health for all."<sup>9</sup> This declaration, which recognizes health as a human right, adheres to the definition of health as put forth by the WHO in 1946 as "a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity."<sup>10</sup> It maintains that primary healthcare is the most effective way to promote this state of being for the world's poor. Grounded in the idea of universal accessibility and coverage on the basis of need, primary healthcare emphasizes disease prevention, health promotion, community participation, self-reliance, and intersectoral collaboration. PHC highlights the fact that certain circumstances, such as political instability, social unrest, and environmental catastrophes, can affect the provision of this good.<sup>11</sup> Its diverse focus is readily evident in the eight elements outlined at Alma Ata regarding future health interventions: Education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child healthcare, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common

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<sup>9</sup> World Health Organization, "Declaration of Alma Ata: International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September 1978," World Health Organization, [http://www.who.int/hpr/NPH/docs/declaration\\_almaata.pdf](http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf) (accessed December 8, 2007). Prior to 1978, public health programs largely targeted specific diseases in developing states; these programs operated autonomously and were never integrated into the overall health systems of each country. Though these efforts did lead to the eradication of smallpox, these short-term interventions did not address the overall burden of disease in the developing world.

<sup>10</sup> David R. Phillips, *Health and health care in the Third World* (New York, NY: Longman Scientific and Technical, 1990), 2.

<sup>11</sup> Lesley Magnussen, John Ehiri, and Pauline Jolly, "Comprehensive Versus Selective Primary Health Care: Lessons For Global Health Policy," *Health Affairs* 23, no. 3 (2004): 168.

diseases and injuries; and provision of essential drugs.<sup>12</sup>

The goals put forth at Alma Ata are the ultimate manifestation of horizontal health initiatives, and though these stipulations were well received and their content above reproach, they were challenged just one year after their emergence in Kazakhstan. In 1979, authors Julia Walsh and Kenneth Warren introduced the idea of selective primary healthcare as an interim strategy in the process of implementing PHC, and in doing so, changed the nature of the discourse on global health spending. Walsh and Warren argued that primary healthcare is idealistic and costly, and that the best way to improve health for the world's poor is to tackle diseases individually. Thus, they emphasized targeted disease prevention and control over the strategies of sustainability and development presented at Alma Ata. It was this transition from integrated primary healthcare to a more selective approach that ignited the impassioned dispute between horizontal and vertical programs that continues to be debated today.

### **A Horizontal Perspective**

Having begun just thirty years ago, this controversy may be midstream in its existence, but it is more acute than ever before. A consequence of globalization, a vast increase in resources, and a global health landscape that is looking bleaker by the day, this altercation has not diminished in fervor, but intensified. In "The Challenge of Global Health," author Laurie Garret captures the force of this debate. An ardent defense of horizontal initiatives, this article condemns the verticalization of global health funding in

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<sup>12</sup> World Health Organization, "Declaration of Alma Ata: International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September 1978," 2.



contemporary society. Although it is highly praised by those who defend integrated measures, “The Challenge of Global Health” is also the victim of a vast array of criticism from individuals, including such renowned scholars and activists as Jeffrey Sachs, who recognize targeted spending as the most efficient way to improve global health.

This article is a critique of health spending policies in underdeveloped states. Garrett contends that while more money is being dedicated to global health than at any previous point in history, these funds are primarily being “stovepiped” down narrow conduits related to a particular illness, and therefore, what limited resources global health has available are being misused.<sup>13</sup> Rather than limit international funding and attention to specific diseases, Garrett suggests that the world community should invest in comprehensive, integrated health programs that will encourage capacity-building, provide for the basic needs of human beings, and increase maternal survival and overall life expectancy. She argues that maternal survival and life expectancy are markers that are indicative of the health of an entire state; if these indices improve, then all health problems are being ameliorated. Moreover, if they are diminishing, then targeted disease initiatives will do little to enhance a population’s general health.<sup>14</sup> Garrett asserts that the verticalization of funding should capitulate to a more generalized approach to global health spending, which strengthens the health infrastructures of developing states and provides an arena within which disease-specific programs can flourish. She notes, “Tactically, all aspects of prevention and treatment should be part of an integrated effort, drawing from countries’ finite pools of health talent to tackle all monsters at once, rather

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<sup>13</sup> Garrett, “The Challenge of Global Health,” 18.

<sup>14</sup> Ibid., 22.

than dueling separately with individual dragons.”<sup>15</sup> Additionally, these broad-based programs will provide a functioning and effective system for saving lives that will remain in place in these states even after attention and resources are diverted away from global health towards another cause or endeavor.<sup>16</sup> Horizontal initiatives build laboratories, clinics, and hospitals, recruit and train healthcare personnel, and construct systems capable of addressing the basic medical needs of citizens. Thus, their impact is a long-term and sustainable one.

Like Garrett, author Lawrence Gostin notes that at some point, funding for health will dry up; it will not remain the favored charity of celebrities and philanthropists forever. Therefore, he too argues that international institutions and organizations working to improve the health of the world’s poor must capitalize on the support of these public and private donations before they disappear.<sup>17</sup> Once these funds are obtained, they must be allocated in a more efficient and effective manner. Driven by public catastrophes, humanitarian crises, and menacing diseases, resources for health are being misallocated; they are being diverted away from the construction of stable, local health systems with the potential to minister to the basic health needs of entire populations.<sup>18</sup> These broad-based programs may not be as glamorous as those that attack high profile diseases such as HIV/AIDS, but they are able to expand the capacities of these states to provide essential health services to their citizens.

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<sup>15</sup> Garrett, “The Challenge of Global Health,” 24.

<sup>16</sup> *Ibid.*, 25.

<sup>17</sup> Lawrence Gostin, “Meeting the Survival Needs of the Worlds’ Least Healthy People: A Proposed Model for Global Health Governance,” *The Journal of the American Medical Association* 298, no. 2 (2007): 227.

<sup>18</sup> Gostin, “Meeting the Survival Needs of the Worlds’ Least Healthy People: A Proposed Model for Global Health Governance,” 224.

Integrated approaches to global health encourage preventative medical actions, including immunizations and family planning; comprehensive activities that foster direct health effects, such as improving sanitation and providing clean water; and those actions that result in subsequent health effects, such as the provision of education and nutrition.<sup>19</sup> Authors Annette Flanagin and Margaret Winker agree with Garrett that these types of complex and multisectoral initiatives are those that are essential to revolutionizing global health. They argue that these programs allocate scarce resources effectively and enable sustainability; they ensure that donors are collaborating with local governments, healthcare personnel, and communities; they prompt integration, rather than compartmentalization.<sup>20</sup>

In “Are we spending too much on HIV?,” author Roger England, an outspoken critic of vertical spending, echoes the sentiments of Garrett by contending that the funds being stovepiped into targeted disease channels would be better spent on general public health initiatives. England asserts that these funds, and particularly those dedicated to HIV/AIDS, should be redistributed in more rational manner in order to overhaul dilapidated public health infrastructures and address the specific needs of local communities. This author goes so far as to suggest that the newly established Global Fund to Fight AIDS, Tuberculosis, and Malaria be redesigned as a basket fund of general health aid.<sup>21</sup>

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<sup>19</sup> Phillips, *Health and health care in the Third World*, 10.

<sup>20</sup> Flanagin and Winker, “Global Health-Targeting Problems and Achieving Solutions: A Call for Papers,” 1382-84.

<sup>21</sup> Roger England, “Are we spending too much on HIV?,” *British Medical Journal* 334, no. 7589 (2007): 344.

International institutions such as the World Health Organization may not advocate such an extreme suggestion as that put forth by England, but many of them do share the desire for a global health strategy centered on horizontal spending and surrounding the goals put forth at Alma Ata. Though the motivations impelling their inclination towards integrated health systems are different, their overall messages are the same. In *The World Health Report 2007—A Safer Future: Global Public Health Security in the 21<sup>st</sup> Century*, the WHO insists that capacity-building is essential for international security; the health infrastructures of states in the South must be strengthened in order to prevent and control epidemics before they can become pandemics.<sup>22</sup> Accordingly, this report suggests that strengthening national health systems is a global responsibility, and recommends cross-sector collaboration within governments, and an increase in resources dedicated to public health personnel, response networks, and preventions campaigns in order to realize this obligation.<sup>23</sup>

In summary, proponents of integrated health programs and spending focus on health as a human right recognized in the *People's Charter for Health*, the *Universal Declaration of Human Rights*, and the *International Covenant on Economic, Social, and Cultural Rights*.<sup>24</sup> These individuals encourage capacity-building in developing states in order to best address the needs of local populations. They contend that horizontal programs renovate the health infrastructures in these countries in a democratic fashion by

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<sup>22</sup> World Health Organization, *The World Health Report 2007 - A Safer Future: Global Public Health Security in the 21<sup>st</sup> Century* (Geneva, Switzerland: WHO Press, 2007), 2-3.

<sup>23</sup> World Health Organization, *The World Health Report 2007 - A Safer Future: Global Public Health Security in the 21<sup>st</sup> Century*, 8.

<sup>24</sup> David Banta, "Economic Development Key to Healthier World," *The Journal of the American Medical Association* 287, no. 24 (2002): 3196.

collaborating with government officials and communities, not just donors. Integrated initiatives address the complexity of ills that affect health, both directly and indirectly, to inspire self-reliance in these states. Indeed, these long-term and sustainable initiatives, which involve integration and cooperation, foster global equity as they raise the capacities of all nations to provide for the health of their citizens in an equitable manner in line with existing technologies and medications.

The success that these initiatives can cultivate is illustrated by the primary healthcare system in place in Cuba. In spite of the many years of embargo by the United States and the loss of support from the Soviet Union after the Cold War, Cuba has managed to maintain a relative amount of technological and economic progress; this success is one that can, in large part, be attributed to its PHC system. The constitution of Cuba recognizes healthcare as the right of every citizen and the responsibility of the government. The principles of the National Healthcare System, as written in Cuba's Public Health Law, include socialized medicine organized by the government, basic services available and free to all, the encouragement of preventative medicine, public participation in healthcare, and a comprehensive approach to the development of the health system.<sup>25</sup> As a result, Cuba's health indices are similar to those of nations with much bigger budgets: Life expectancy is seventy-five years for men and seventy-nine years for women, and the country's infant mortality rate is 5.0 per 1,000 live births.<sup>26</sup>

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<sup>25</sup> Magnussen, Ehiri, and Jolly, "Comprehensive Versus Selective Primary Health Care: Lessons For Global Health Policy," 170.

<sup>26</sup> World Health Organization, "Core Health Indicators - Cuba," World Health Organization, [http://www.who.int/whosis/database/core/core\\_select\\_process.cfm](http://www.who.int/whosis/database/core/core_select_process.cfm) (accessed December 9, 2007).

While primary healthcare was, and continues to be one of the foremost strategies for horizontal programming, a popular alternative to this method is the sector-wide approach. (SWAp) These initiatives involve governments and donors working together; each has responsibilities and rights. Rather than focus on a single disease, or a project aimed at combating that disease, SWAp encourage agents to contribute to the funding of an entire sector; these programs focus on the improvement of all aspects of a state's health policies, rather than on disease-specific interventions. This transition is illustrative of a shift in policy, as well as in the institutional and financial frameworks within which healthcare is provided.<sup>27</sup>

Sector-wide approaches were successfully introduced in Ghana. This African state decided to reform its healthcare system and towards that end, it brokered agreements with international agencies and donors to pool and allocate foreign aid according to a previously agreed upon agenda. As a result, in 1997 and 1998, immunization coverage increased by nearly 20 percent.<sup>28</sup>

Despite the favorable outcomes of these horizontal initiatives and the fact that the goals of this approach are widely accepted, integrated programs have been slow to be enacted. In *Development as Freedom*, author Amartya Sen articulates a phrase that exemplifies one of the principal shortcomings of these strategies stating, "Broader approaches are often harder to 'sell' than narrowly focused reforms that try to achieve

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<sup>27</sup> A. Cassels and K. Janovsky, "Better health in developing countries: are sector-wide approaches the way of the future?," *The Lancet* 352, no. 9142 (1998): 1778.

<sup>28</sup> Tore Godal, "Immunization against poverty," *Tropical Medicine and International Health* 5, no. 3 (2000): 162.

‘one thing at a time.’”<sup>29</sup> Opponents of horizontal programs contend that it is difficult to rally and maintain support and funding for integrated approaches, which do not tackle any specific objective or yield results quickly. Moreover, these critics argue that initiatives centered on improving general public health systems ignore the urgency of exceptional diseases such as HIV/AIDS, which are killing millions of people each year. A threat to international and domestic security, these diseases need special attention and should be prioritized on the global public health agenda.<sup>30</sup>

### **A Vertical Outlook**

Vertical programs may possess a near monopoly relative to global health spending, however, these schemes are not beyond reproach. From Laurie Garrett to Roger England, proponents of integrated measures have levied strong criticisms against the verticalization of health funding. This approach, which is top-down and donor driven, creates a supply-and-demand problem. The funds and resources provided by donors are not on par with recipient needs; donor preferences do not reflect local proclivities.<sup>31</sup> Desperate for aid, these countries skew their priorities in order to align them with available resources; this creates a supply-and-demand imbalance. Critics maintain that vertical programs draw attention away from other health problems, weaken public health systems, and contribute to brain drain in the developing world.<sup>32</sup> In terms of debilitating health systems, scholars challenge that vertical efforts are uncoordinated and lead to overlap, fragmentation,

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<sup>29</sup> Amartya Sen, *Development as Freedom* (New York, NY: Anchor Books, 1999), 126.

<sup>30</sup> Gregory K. Folkers and Anthony S. Fauci, “The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance,” *The Journal of the American Medical Association* 286, no. 4 (2001): 459.

<sup>31</sup> Kates, “Global health funding: a glass half full?,” 187.

<sup>32</sup> Garrett, “The Challenge of Global Health,” 14-38.

duplication, and waste.<sup>33</sup> These programs each have their own priorities, budgets, planning, and reporting requirements; they increase the administrative burden on strained health ministries in developing states. Many critics charge that when vast sums of money and resources enter into regions with little to no health infrastructure to support them, they are ineffective. Finally, it is often noted that vertical efforts ignore the broader context of development and social justice within which strategies to improve global health should exist.<sup>34</sup>

These criticisms represent only one side of the vertical approach to global health spending. Indeed, it is the merits of this system that allow it to maintain a position of primacy in the international health hierarchy. The verticalization or stovepiping of aid encourages global action, amasses international attention and resources, fosters the emergence of innovative participatory and governance mechanisms, and promotes results-based funding.<sup>35</sup> In large part, those who champion vertical initiatives cite the popularity of these programs, which are supported by both the public and private sectors, and are capable of gathering and maintaining support for their causes. Furthermore, proponents note that vertical programs have raised awareness of all global health issues, and have the ability to accumulate funding for these parallel measures as well.

In 2000, the WHO established the Commission on Macroeconomics and Health, chaired by Jeffrey Sachs, in order to assess the relationship between health and global development. In a summary of the report produced by this body, Sachs states,

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<sup>33</sup> Magnussen, Ehiri, and Jolly, "Comprehensive Versus Selective Primary Health Care: Lessons For Global Health Policy," 170.

<sup>34</sup> Ibid., 170.

<sup>35</sup> George J. Schieber, "Financing Global Health: Mission Unaccomplished," *Health Affairs* 26, no. 4 (2007): 921-934.



“Extending coverage of crucial health services, including a relatively small number of specific interventions, to the world’s poor could save millions of lives each year, reduce poverty, spur economic development, and promote global security.”<sup>36</sup> Moreover, it maintains, “There is an urgent need for more investments in new and improved technologies to fight the killer diseases.”<sup>37</sup> The commission identified these illnesses as HIV/AIDS, tuberculosis, and malaria, and calculated that \$25 billion USD per year are needed to control these diseases in the developing world.

Published in 2001, the *Report on Macroeconomics and Health: Investing in Health for Economic Development*, profoundly impacted the behavior of its benefactor, the World Health Organization, as well as international health agencies more generally. With regards to the former, author Fiona Godlee argues that in spite of its purported commitment to integrated primary healthcare, the most visible, successful, and well-publicized efforts of the WHO are targeted intervention programs such as the Multi-Country AIDS Program for Africa. These disease-specific initiatives are funded by extra-budgetary contributions from donor states; these funds exist outside of the WHO’s regular budget. Outnumbered in the World Health Assembly, these programs shift control back to donor states, which embrace their well-defined goals and strategies, outcome measurements, and financial accountability.<sup>38</sup>

The United Nations is another international organization that has practiced vertical programming and spending. (UN) The UN Millennium Development Goals are

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<sup>36</sup> Banta, “Economic Development Key to Healthier World,” 3195.

<sup>37</sup> Ibid., 3197.

<sup>38</sup> Fiona Godlee, “The World Health Organization: WHO’s special programmes: undermining from above,” *British Medical Journal* 310, no. 6973 (1995): 178.

demonstrative of this fact. Representative of the consensus of all the world's states and predominant international institutions, the Millennium Development Goals form a framework of targets for meeting the most urgent needs of the world's poor by 2015. In terms of global health, these goals are to "promote maternal health," and "combat HIV/AIDS, malaria, and other diseases."<sup>39</sup> It seems that the world's leaders have agreed that vertical programs represent the best use of their money and resources.

PEPFAR, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and the Bill and Melinda Gates Foundation—three of the largest global health giving organizations—are all primarily dedicated to the eradication of specific diseases in the developing world. Those who favor vertical approaches stress that the prevalence of these organizations, and their position at the top of the healthcare hierarchy, is indicative of their benefits and advantages. In "The dangers of attacking disease programmes for developing countries," authors Simon Collins et al. argue that priority disease programs have proven capable of making significant strides in short periods of time. For example, the Global Fund to Fight AIDS, Tuberculosis and Malaria, which was established in 2002, already contributes two-thirds of all funding for tuberculosis and malaria, and provides nearly 20 percent of funding for HIV/AIDS programs throughout the world. These authors assert that vertical programs have proven to be effective, and therefore, critics should refrain from condemning that which is working to save lives and affect global health reforms.<sup>40</sup>

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<sup>39</sup> United Nations, "United Nations Millennium Development Goals," United Nations, <http://www.un.org/millenniumgoals/index.html> (accessed December 7, 2007).

<sup>40</sup> Simon Collins, Brook K. Baker, Gregg Gonsales, and Marco Gomes, "The dangers of attacking disease programmes for developing countries," *British Medical Journal* 335, no. 7621 (2007): 646.

Vertical programs are embodied by directly-observed therapy, short-course treatments. (DOTS) This strategy, used throughout the developing world to treat tuberculosis, attempts to control all aspects of a disease; from prevention to treatment to care during remission, DOTS aim to constrain and reverse the spread of the world's most infectious diseases.<sup>41</sup>

Advocates of vertical spending insist that infectious diseases, and particularly HIV/AIDS, are extraordinary and demand unique and potent responses. Citing the oft noted United Nations *Human Development Report 2005* which states, "the HIV/AIDS pandemic has inflicted the single greatest reversal in human development," author Peter Piot defends the prioritization of this disease claiming that no other global problem, barring extreme poverty and nuclear war, merits to rank among HIV/AIDS in terms of the devastation it has, and will continue, to cause.<sup>42</sup> Furthermore, the publicity which this disease has generated, and the funds and resources it continues to elicit from donors, will heighten awareness of other health issues and, if used appropriately, provide an opportunity for developing states to improve their crumbling health infrastructures.<sup>43</sup>

Despite these purported assets, critics of this approach remain wary of its long-term benefits. Accordingly, an analysis of the solution that seeks to incorporate both comprehensive and vertical measures is imperative to our examination of the future of global public health.

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<sup>41</sup> Darrell Tan, Ross Upshur, and Nathan Ford, "Global Plagues and the Global Fund: Challenges in the Fight Against HIV, TB, and Malaria," *BMC International Health and Human Rights* (April 1, 2003), <http://www.biomedcentral.com/1472-698X/3/2>, 2.

<sup>42</sup> Peter Piot, "AIDS: from crisis management to sustained strategic response," *The Lancet* 368, no. 9534 (2006): 526.

<sup>43</sup> Paul de Lay, Robert Greener, and Jose Antonio Izazola, "Are we spending too much on HIV?," *British Medical Journal* 334, no. 7589 (2007): 345.

## **A Synthesis of Strategies**

Legitimate arguments, ardent supporters, and the ability to save lives characterize both horizontal and vertical approaches to global health spending and programming. Though these strategies appear to be irreconcilable in terms of their methods and aims, integrated approaches need not compete with vertical initiatives; these programs are not mutually exclusive, and scholars and activists alike should refrain from painting them in this manner. A synthesis between integrated and selective measures can be developed. In a sense, this process has already begun. From Laurie Garrett to Jeffrey Sachs, individuals on both sides of this debate consider a reconciliation of these strategies to be the ultimate end of global health. In fact, the differences that arise between their positions are not a matter of emphasizing one strategy at the expense of the other, but stem from varying ideas over what approach is more beneficial to the improvement of global health in the developing world right now.

The time for the amalgamation of these approaches is the present; millions of lives are affected by the manner in which global health funds are spent, and there is no time to waste in ensuring that they are allocated in a more beneficial manner. The endorsement of Laurie Garrett, who argues that targeted disease programs should be integrated within larger public health initiatives, will be critical to the establishment of a compromise between these endeavors.<sup>44</sup> Supported by Jeffrey Sachs, who contends that the problems of global health can be solved by raising more capital and spending it on disease-specific as well as comprehensive efforts aimed at improving overall health

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<sup>44</sup> Garrett, "The Challenge of Global Health," 24.

systems, these explanations should be sufficient to rally a coalition of experts and activists to achieve this lofty goal.<sup>45</sup> Already, distinguished scholars such as Paul Farmer agree that an approach that combines both horizontal and vertical elements would be extremely effective.<sup>46</sup> A compromise between these programs is not only advocated by the most renowned proponents of global health giving and spending, but is echoed by interested parties at all levels of this controversy. In a joint article entitled, “Global Plagues and the Global Fund: Challenges in the Fight Against HIV, TB, and Malaria,” authors Darrell Tan, Ross Upshur, and Nathan Ford contend that the future of global health depends upon the successful union of these strategies; vertical programs must complement horizontal endeavors in order to create a sense of balance between the world’s most fatal diseases and the programs aimed at the absence of capabilities and resources that initially predispose men and women to poor health.<sup>47</sup>

Global health, a policy issue on the political agenda of every state leader, has billions of dollars at its disposal and thousands of agencies dedicated towards improving its current state in the developing world. Still, millions of men and women are dying each year from preventable illnesses while others are suffering unnecessarily from diseases for which mankind has long possessed therapeutic remedies. It appears that contemporary spending policies are not meeting the basic health needs of the world’s poor. While I respect vertical initiatives and applaud their success in garnering attention

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<sup>45</sup> Jeffrey D. Sachs, “Beware False Tradeoffs,” *Foreign Affairs* (January 23, 2007), [http://www.foreignaffairs.org/special/global\\_health/sachs](http://www.foreignaffairs.org/special/global_health/sachs).

<sup>46</sup> Paul Farmer, “From ‘Marvelous Momentum’ to Health Care for All,” *Foreign Affairs* 86, no. 2 (2007): 155-59.

<sup>47</sup> Tan, Upshur, and Ford, “Global Plagues and the Global Fund: Challenges in the Fight Against HIV, TB, and Malaria,” 4.

and resources for global health, I do not believe they are capable of revolutionizing this public sphere. Though they have, and will continue to save lives, alone, they are insufficient to provide for the health of people in the developing world. I am not proposing that these programs be eradicated, indeed, I am a strong proponent of synthesizing vertical and integrated initiatives. At the same time, however, horizontal approaches to programming and spending must be allocated the predominant share of resources dedicated to global health, and be those which are primarily implemented in the South. These strategies will improve the health infrastructures of developing states, and increase the ability of these countries to provide healthcare for both their citizens who are suffering from specific illnesses, as well as those who are not.

An excellent example of the necessity of horizontal initiatives as a prerequisite for the implementation of vertical programs is found in the African state of Botswana. In August 2000, the Bill and Melinda Gates Foundation, the Harvard AIDS Initiative, and the pharmaceutical companies Bristol-Myers Squibb and Merck joined forces with the government of Botswana to launch a nation-wide HIV/AIDS treatment program. When this project began, 37 percent of Botswana's population between fifteen and forty was infected with HIV; it had the highest infection rate in the world. With a relatively stable government in Gaborone, a decent infrastructure in place, and financial and strategic support from the donors listed above, this collaborative program seemed destined to succeed. However, in light of insufficient healthcare personnel and the absence of a healthcare system to execute the initiative, supporters of this program quickly realized that they would need to build clinics and laboratories and recruit or train medical workers

to hand out antiretroviral drugs in Botswana.<sup>48</sup> This account illustrates the importance of realizing capacity-building efforts for the implementation of selective healthcare measures. Proponents of integrated approaches to global health spending are correct to emphasize the benefits of providing for the basic health needs of all citizens before tackling individual diseases.

I agree with Garrett that a synthesis of these strategies, grounded in the initial establishment of horizontal, capacity-building programs, is possible. Beyond this acknowledgment, however, I wish to suggest a plan for moving out of the arena of intellectual debate into the realm of action. Horizontal programs may not currently be galvanizing resources and support, however, neither did HIV/AIDS initiatives until the outbreak of this disease in the United States of America, and the successful agenda-setting efforts of activists and officials in this country. By studying how this disease—the most potent force in global health’s history—was placed on the American public and political agendas, relative agents can learn what techniques to apply to integrated initiatives in order to foster general awareness, encourage action, and be made a priority for politicians.

The following chapter will examine the arguments of five leading scholars in the field of policymaking, as well as synthesize their works in order to form a postulate with the ability to explain the placement of HIV/AIDS on the American agendas. Although many would argue that accumulating and sustaining interest in, and funding for horizontal initiatives is impossible, change can be affected. Like vertical programs, these

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<sup>48</sup> Garrett, “The Challenge of Global Health,” 20.

measures can capture the international community's imagination and ignite the spark that will propel global public health into a new, and more successful, stage in its brief history.



## **CHAPTER THREE : THE POLICYMAKING PROCESS**

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### **Implications of Agenda-Setting and Policy Formation**

The War in Iraq, immigration, and healthcare—these are several of the most compelling contemporary issues in the United States of America. These are the problems that are dominating both the public and political agendas, and consequently, the attention of elected officials and appointees, and absorbing the vast majority of this country's wealth and resources. How have these items come to define the state of this nation? Why have these subjects emerged to the top of the list of issues with which the government and American citizens are concerned? Contrary to popular belief, these topics have not always maintained a prominent position on this country's to-do list; indeed, their placement on the agenda of the world's only hegemon was absolutely intentional.

Agenda-setting and policy formation may appear to be boring, dry, dull processes assigned to the care of government officials gathered in heavily draped, wood-paneled rooms and broadcast on C-SPAN. However, these procedures are at the heart of a state's living history. Agenda-setting and policy formation are not simply a matter of enacting statutes and laws that hold little relevance for the average citizen, but of transforming societal norms and guiding the vision and values of a state and its people. No individual remains outside the domain of these practices. While policy decisions will ultimately be made by government authorities, all citizens—whether mobilized by activists, celebrities, or the media—are able to influence those men and women whom they elected, and impact the formation of the American political agenda and the public policies that spring forth from it. What becomes an issue, and how that problem is addressed once it is on the

agenda, has grave implications for the present and future of America, as well as every other state. These decisions affect how our country, and we as its citizens, will be remembered; it affects the world in which we live as well as the world generations to come will inherit.

In an international system dominated by the nation-state, agenda-setting and policy formation have been, and continue to be, the central mediums through which change is brought to fruition. Without understanding how problems become significant issues on the public and political agendas in the first place, and how policy alternatives are formulated to respond to them, one would find it very difficult to mount a successful campaign to reform nearly any aspect of society. As we have seen in earlier chapters, HIV/AIDS has become a dominant force on the American agendas largely to the exclusion of other global health crises. How was this accomplished? Moreover, how have vertical approaches, which are so intimately linked to HIV/AIDS initiatives, become the favored policy solutions to reform international public health? How did they become the norm?

Many individuals have become disillusioned with the American government and its elitist, corporate focus. However, it is critical that one recognizes that agenda-setting and policy formation are the most efficient ways to adjust the parameters of this focus, redefine problems, and determine a more legitimate, peaceful, and sustainable generation of American politics. Agenda-setting and policy formation are multifaceted and complicated processes. In order to grasp the primary tenets of these procedures and grapple with their implications for the future of global health spending, I will be

introducing five prominent scholars, with diverse backgrounds and arguments, in this field. After giving a brief synopsis of the observations put forth by each of these individuals, I will synthesize their explanations in order to form a single, coherent postulate capable of elucidating how HIV/AIDS was placed on the public and political agendas, how vertical solutions became an exemplar, and how the American agendas can be reset with a new nucleus and a new strategy for global health financing.

For too long, the American people, with regards to global health spending, have been narrowly focused on one disease and a single response to that disease; it is high time for a change. If we continue along our current path of global health expenditures, we will see, in our lifetime, the arrival of new, menacing diseases, the collapse of states as citizens succumb to treatable and fatal illnesses alike, and the deaths of millions of men and women in both the developed and developing worlds. Agenda-setting and policy formation matter, and the decisions made by government officials meeting in those heavily draped, wood-paneled rooms, and their consequences will not ultimately be measured in dollars, but in human lives.

### **An Expert Synopsis**

A renowned scholar, John W. Kingdon is the author of *Agendas, Alternatives, and Public Policies*, a seminal work in the field of agenda-setting and policy formation. Kingdon emphasizes agenda-setting and alternative specification as the most critical components of the public policymaking process. The former narrows down the innumerable list of potential subjects to those that will actually be addressed, while the latter reduces the number of possible alternatives to those from which the decision will ultimately be

made.<sup>1</sup> Kingdon understands these practices as being guided by a very limited set of actors—essentially, those working in and around the government. He contends that elected officials and their appointees are the most powerful actors relative to the placement of various items on the political agenda, while specialists in the bureaucracy and policy communities influence the generation of alternatives to address these issues.<sup>2</sup>

Kingdon uses a revised version of the Cohen-March-Olsen garbage can model of organizational choice to frame and explain the processes of agenda-setting and alternative specification.<sup>3</sup> According to this author, the federal government is an organized anarchy encompassing three branches of processes: problems, policies, and politics.

Theoretically, all participants could be involved in all of these operations, however, as was stated in the aforementioned paragraph, there is an established history of specialization with regards to each of these streams. Nevertheless, both agenda-setting and alternative specification are powerfully guided and constrained by these activities.

Problem definition is of the utmost importance in the realm of agenda-setting, and the political stakes involved in this task are extremely high, as the manner in which these issues are perceived readily determines what person or group has responsibility, control, and power over them. Not all conditions come to be defined as problems. In order for

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<sup>1</sup> John W. Kingdon, *Agendas, Alternatives, and Public Policies* (New York, NY: HarperCollins College Publishers, 1995), 3-4.

<sup>2</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 19.

<sup>3</sup> Ibid., 19, 85-86. Cohen et al. maintain that “A choice opportunity thus is ‘a garbage can into which various kinds of problems and solutions are dumped by participants as they are generated. The mix of garbage in a single can depends on the mix of cans available, on the labels attached to the alternative cans, on what garbage is currently being produced, and on the speed with which garbage is collected and removed from the scene.’” As Kingdon aptly points out, this does not signal a rational decision making process, but rather, a series of outcomes dependent on what garbage is placed in the can and how it is processed; this is not unlike the act of placing an item on the agenda and generating alternatives to address it.

this transformation to occur, government officials and those close to them must have both the desire and the will to affect change in these arenas. This generally occurs when they consider these conditions in light of their personal values, recognize unfavorable comparisons between people or between the United States and other countries, or substitute the categories within which these items are placed.<sup>4</sup>

More specifically, Kingdon argues that problems are placed on the political agenda when they draw the attention of policymakers as a result of systematic indicators, focusing events, or feedback. Policymakers look to indicators to assess the significance of a problem, as well as to monitor any substantial changes in it. Focusing events act as brightly colored signs, illuminating and reinforcing preexisting perceptions, as well as drawing attention to areas that may later become central policy concerns. Finally, feedback gives policymakers the opportunity to evaluate current programs and assess their efficacy and performance.<sup>5</sup>

While problem definition is essential for placing an item on the agenda, its connection to a viable alternative increases the likelihood that this item will not only rise on the agenda, but also become a principal concern for policymakers. Alternative specification typically falls within the purview of specialists, both in and outside of government, in a given policy area. While many ideas are proposed and circulated in these communities, in what Kingdon deems a policy “primeval soup,” those that survive to the level of legitimate consideration typically meet the following criteria: technical feasibility, value acceptability, tolerable cost, anticipated public acquiescence, and a

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<sup>4</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 114.

<sup>5</sup> *Ibid.*, 113.

reasonable chance of receptivity among policymakers.<sup>6</sup> In a departure from the conventional realist tenets that have traditionally guided political thought, Kingdon argues that power, influence, pressure, and strategy cannot explain agenda-setting and policy formation on their own. Rather, public policy should be understood in terms of the quality, content, and characteristics of the ideas themselves.<sup>7</sup>

Policymaking is not simply affected by problem definition and the creation of policy alternatives, but by politics. The political stream, which includes changes in the national mood, election results, the introduction of new administrations, variations in ideological or partisan distributions in Congress, and even interest group lobbying, has a notable impact on the formation of the political agenda and policy alternatives.<sup>8</sup>

It is important to note that no one stream, on its own, is likely to lead to agenda and policy changes. The key to setting a new agenda and transforming contemporary practices is the coupling of these strands at critical junctures in time. It is when the three streams of processes—problems, policies, and politics—merge together that a mighty river capable of placing an item on the agenda, and enacting the policies created by specialists to address it, is formed.<sup>9</sup>

Like Kingdon, author E.E. Schattschneider argues that in a democracy, competing leaders and organizations are those who engender or subordinate issues and define policy alternatives. While the public participates in these decision-making processes to an

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<sup>6</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 131.

<sup>7</sup> Ibid., 125.

<sup>8</sup> Ibid., 162.

<sup>9</sup> Ibid., 19.

extent, they are not the primary agents of political change.<sup>10</sup> Public participation generally manifests itself in active leaders and diverse groups who organize and compete with one another to spotlight what is, for them, a particularly relevant issue.

In *The Semi-Sovereign People: A Realist's View of Democracy in America*, Schattschneider, true to his realist convictions, emphasizes the competitive nature of this field by contending that conflict is at the root of all politics. Conflicts, which both divide and unite people, are constantly in competition with one another to survive and distribute power; power is inherently implicated in political outcomes.<sup>11</sup> There are billions of conflicts, or issues, in society today, however, only a very small number of these will ever rise to the political agenda; reducing the number of conflicts is essential to political stability. Fortunately for policymakers, major issues dominate, overwhelm, and subordinate multitudes of lesser ones. The dominance of conflicts is a product of their intensity and visibility, their capacity to erase other issues, and their ability to transcend traditional boundaries to unite parallel groups of people.<sup>12</sup>

The displacement of conflict is the prime instrument of political strategists as it allows them to demote competing items while simultaneously propelling their own favored issues into the realm of political prominence. Exploiting racial and sectional antagonisms, sectional alignments, and urban-rural conflicts all have the intended effect of making some conflicts irrelevant and others important.<sup>13</sup>

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<sup>10</sup> E.E. Schattschneider, *The Semi-Sovereign People: A Realist's View of Democracy in America* (New York, NY: Holt, Rinehart and Winston, 1960), 141.

<sup>11</sup> Schattschneider, *The Semi-Sovereign People: A Realist's View of Democracy in America*, 2, 64, 77.

<sup>12</sup> Ibid., 66-68, 74.

<sup>13</sup> Ibid., 73.

In “The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines,” author Kenneth R. Rutherford takes an approach to agenda-setting practices that is quite distinct from the previous two authors. Rutherford does not look to government officials, organizations, or elected leaders to set the political agenda, but rather, argues that NGOs can, and do, play a prominent role in influencing these agendas, both domestically and internationally. This author takes a constructivist approach to this convention, and assumes that because norms are socially constructed, NGOs can significantly affect the agenda-setting process by placing items on the agenda, and once there, by further manipulating the framework within which they are viewed and understood. Rutherford notes, “NGOs can introduce a norm and translate it into a powerful instrument with lasting influence by initiating an issue and then controlling it on the international political agenda.”<sup>14</sup>

There are two levels of agenda-setting: Cognitive agenda-setting and norm agenda-setting. (CAS, NAS) The former explains how NGOs garner attention for an issue and subsequently place it on the political agenda. NAS, on the other hand, is indicative of how NGOs shape the state or government’s perception of a problem. There are several other components of agenda-setting that can be described in terms of these two levels—framing, schema, and priming. Framing is the selection of particular elements within an issue in order so that people will consider that problem in a certain way. Schema centers on how individuals organize their thoughts; it is concerned with reducing and synthesizing complicated information into a manageable number of frames

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<sup>14</sup> Kenneth R. Rutherford, “The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines,” *World Politics* 53, no. 1 (October 2000), 76-77.



so that individuals are not overwhelmed by it. Finally, there is priming. Closely linked to schema, priming is the process by which the frames that are produced by the schema operations are activated. Priming uses frequent and intense media exposure to trigger these previously learned ideas and images.<sup>15</sup>

Essentially, Rutherford contends that NGOs can place an item on the agenda, control the conditions under which it is examined, and affect lasting change by resourcefully utilizing the agenda-setting tools of framing, schema, and priming. This includes expanding the scope of the conflict by inviting the general public into the argument, generating intense media coverage, categorizing the issue in a new and unique fashion, using systematic indicators, appealing to moral and ethical arguments, and emphasizing the humanitarian aspects of an issue.<sup>16</sup>

NGOs may not have the resources or power of government officials, but by making an issue more visible and by inviting the American public to become more involved in its future, NGOs weaken the monopoly held by government authorities on various problems and issues, and make policymakers more sensitive to civilian and organized influence.<sup>17</sup>

Like Rutherford, author Deborah A. Stone takes a constructivist approach to agenda-setting and policy formation. She argues, “Our understanding of real situations is always mediated by ideas; those ideas in turn are created, changed, and fought over in

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<sup>15</sup> Rutherford, “The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines,” 78.

<sup>16</sup> Ibid., 75-114.

<sup>17</sup> Ibid., 98.

politics.”<sup>18</sup> Stone holds that causal ideas are the key to agenda-setting. She asserts that difficult situations become problems when they are seen as caused by human actions, and amenable to human intervention; this transition is vital to placing items on the political agenda. Problems must be interpreted within the sphere of human influence and control, as opposed to those that are caused by fate and nature.<sup>19</sup>

The need to assign responsibility and authority is central to Stone’s agenda-setting theory. She maintains that political actors create and compose causal stories in an intentional and deliberate manner calculated to gain support for their factions and supporters, while simultaneously attributing harms and grievances to the will of others, in order so that they can obtain the power to remedy them, or insist that the government do so. These men and women fabricate narrative stories designed to manipulate an issue’s characteristics, while appearing to present the facts. It is important to note that the competition between political actors to create and control causal stories does not stop once these items reach the political agenda.<sup>20</sup> Stone contends, “Causal stories continue to be important in the formulation and selection of alternative policy responses, because they locate the burdens of reform very differently.”<sup>21</sup> These theories challenge or protect the existing social order by condemning some as perpetrators of the problem or grievance at hand, while at the same empowering others to address the issue.<sup>22</sup>

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<sup>18</sup> Deborah A. Stone, “Causal Stories and the Formation of Policy Agendas,” *Political Science Quarterly* 104, no. 2 (1989): 282.

<sup>19</sup> Stone, “Causal Stories and the Formation of Policy Agendas,” 281, 284.

<sup>20</sup> *Ibid.*, 282.

<sup>21</sup> *Ibid.*, 283.

<sup>22</sup> *Ibid.*, 296.

Although her primary purpose is to put forth an explanation of how agendas are set in the first place, Stone also delves into the realm of policy formation, and in a statement reminiscent of Kingdon, she notes that causal theories are more likely to capture the attention of policymakers “if the proponents have visibility, access to media, and prominent positions; if the theory accords with widespread and deeply held cultural values; if it somehow captures or responds to a ‘national mood;’ and if its implicit prescription entails no radical redistribution of power or wealth.”<sup>23</sup>

Author Toshio Takeshita writes a very similar script to Stone, but starring a very different actor—the media. In “Exploring the Media’s Roles in Defining Reality: From Issue-Agenda Setting to Attribute-Agenda Setting,” Takeshita argues that reality definition, a concept that parallels Stone’s causal narratives, is a function of the media. The media is the agent that reconciles external reality and internal functionings. The media influences people’s cognitions and consequently, the choices they make based on them. Accordingly, the media has definite repercussions for democratic politics. For Takeshita, the media’s hold on the general public—including policymakers and the influence the public exerts on them—allows it to set an agenda that determines, to a significant degree, that of the public and subsequently, the government.<sup>24</sup> Takeshita notes, “Determining what to select for attention and what to ignore among a number of existing issues means determining the perspective you apply to view the political world

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<sup>23</sup> Stone, “Causal Stories and the Formation of Policy Agendas,” 294.

<sup>24</sup> Toshio Takeshita, “Exploring the Media’s Roles in Defining Reality: From Issue-Agenda Setting to Attribute-Agenda Setting,” in *Communication and Democracy: Exploring the Intellectual Frontiers in Agenda-Setting Theory*, ed. Maxwell Combs, Donald L. Shaw, and David Weaver (Mahwah, NJ: Lawrence Erlbaum Associates, 1997), 15, 20.

as a whole. Agenda-setting is indeed another expression of the reality definition function of the media.”<sup>25</sup>

In the technological world in which we live, the media is increasingly able to structure the cognitive functions of its audience. In fact, Takeshita maintains that the transfer of saliency from the media to individuals’ consciousness is the primary component of agenda-setting. He argues that this process can be operationalized on two dimensions. The first is that of issue-agenda setting and the second is that of attribute-agenda setting. (IAS, AAS) Similar to CAS, IAS alludes to the transmission of issue salience while AAS, reminiscent of NAS, refers to the transmission of attribute or characteristic significance. Takeshita stresses the importance of agenda-setting and policy formation, and the key role played by the media in these processes. He argues that the media is not only influencing what we think about, but it is also shaping the way in which we think about it. Consequently, it determines the items and issues we want to see placed on the political agenda.<sup>26</sup>

As disparate as the above authors may seem with regards to their different arguments, emphases, and actors, these scholars share a common objective—to explain the complicated processes of agenda-setting and policy formation that are so integral to the future of the United States, its citizens, and the world more broadly. Indeed, when one looks beyond their obvious dissimilarities, there are a number of links that bind their arguments to one another and allow for a synthesis of their works.

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<sup>25</sup> Takeshita, “Exploring the Media’s Roles in Defining Reality: From Issue-Agenda Setting to Attribute-Agenda Setting,” 20.

<sup>26</sup> Ibid., 20-23, 26.

Behind every item that is placed on the agenda and every policy that is proposed to address it, there are thousands of men, women, and children who are affected by the promotion of that issue, or the signing of that alternative into action. In this case, we are looking to those who are, and have been affected by a lack of healthcare in the developing world, and who have suffered because of insensitive and mismanaged initiatives to address their needs. By fusing the theses of Kingdon, Schattschneider, Rutherford, Stone, and Takeshita with regards to agenda-setting and policy formation, we can develop an explanation capable of determining how HIV/AIDS was placed on the agenda, and how vertical initiatives were introduced to address it. Consequently, we can use those details to reset the global health agenda and generate new, more sustainable alternatives to confront the crises that are threatening to unravel the thread binding our increasingly interdependent world together.

### **Expanding the Parameters of Agenda-Setting and Policy Formation**

The implications of agenda-setting and policy formation have been made clear; these topics matter. They matter so much, in fact, that some of the world's brightest minds have dedicated themselves to tackling these multifaceted processes to determine the actors and actions involved. Thus far, we have looked to the works of Kingdon, Schattschneider, Rutherford, Stone, and Takeshita to draw a diverse picture of these practices and those who orchestrate them. Taken separately, these authors present specific information that highlights a certain area or activity that is vital to these topics. However, when combined, their explanations unite to form a powerful argument that not only addresses all relevant areas and activities, but which is capable of explicating

today's manifold issue campaigns and the broad spectrum of policy alternatives being produced to respond to them. The section that ensues will develop the features of this fusion, and the final product will be representative of the general framework within which the following chapters will be considered.

Agendas are at the heart of this conversation and therefore, before we go any further, it is critical to establish how we are defining this item. There are two different definitions of agendas that embody the characteristics assigned to these entities by the authors we have examined. The first description, put forth by Kingdon, maintains that agendas are "the list of subjects or problems to which government officials, and people outside of government closely associated with those officials, are paying some serious attention to at any given time."<sup>27</sup> Takeshita, on the other hand, argues that agendas are "objects accorded saliency in the media content or in people's consciousness."<sup>28</sup> While useful, both of these definitions are limited by the expertise of their authors and their emphases more generally, and are unable to provide a definition that will suffice for our purposes here.

Nevertheless, if we combine these definitions and contend that agendas are *the list of subjects or problems that are accorded saliency in the media and people's consciousness, and which, consequently, have captured the attention of government officials and those closely associated with them including bureaucrats, specialists, and various governmental and non-governmental organizations*, then we have a definition of

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<sup>27</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 3.

<sup>28</sup> Takeshita, "Exploring the Media's Roles in Defining Reality: From Issue-Agenda Setting to Attribute-Agenda Setting," 20.

agendas—henceforth referred to as public agendas—that is representative of many contemporary issues and the discourse that is associated with them. Every individual in society has a stake in what is placed on the agenda and what is not; each person can and does, by act or accident, contribute to this placement. That said, one must recognize that government officials and appointees are those who ultimately make decisions regarding what will become a predominant agenda item and receive the government resources and attention necessary to affect change in that area. Throughout this thesis, I have referred to the political agenda, and by this, I am referring to *those preeminent issues that have moved into position for some sort of serious authoritative decision by the state.*<sup>29</sup> In many ways, positioning on the political agenda is the logical consequence of placement on the public agenda. However, because a divide does exist between them, and an item's assignment on one or the other is extremely relevant, it is important to distinguish between public and political agendas.

Both public and political agendas play a part in determining what a state and its people consider pertinent and pressing, and also what steps they will take to confront it. Granted, government representatives are primarily those who are making the final decisions in terms of what is officially addressed and considered. At the same time, in the democratic society in which we live, where access to information is ever more readily available, these elected individuals are heavily influenced by their constituents, organized

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<sup>29</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 142. Kingdon refers to what I am terming political agendas as decision agendas, and these include those subjects, such as legislative and presidential actions, that are moving into position for a commanding decision.

lobbying efforts, and the media. Thus, the definitions of agendas outlined above are meant to encompass all of these actors and recognize the critical roles they play.

Policy formation is the second stage of the policymaking process and refers to the generation of various policy options and alternatives that could be implemented to address the issues currently resting on the agenda. Policy formation includes the initial spark of ideas, the introduction of bills, various speeches and conversations—both formal and informal, the drafting of proposals, amendments to those bills, and so on and so forth.<sup>30</sup> These options are generally put forth by specialists in a given policy area, however, these men and women are affected by the way in which these items have been framed by the media, activists, and the government. While this process is certainly a creative one, it is also extremely selective and of grave importance, considering that its products dictate the future direction of a state and its people.

Agenda-setting and policy formation are two of the most important stages in the policymaking process as they determine both what issues will be placed on the agenda, and once there, how they will be addressed. There are innumerable conflicts and issues in the world, and yet, only a small few ever find their way onto the agenda. Indeed, the ones who make it have to subordinate and displace millions of other issues in order to arrive there.<sup>31</sup> The question thus remains, how are issues placed on the agenda in the first place?

The process of agenda-setting centers on reality definition. In order for a situation or problem to become an issue worthy of a place on the agenda, it must be considered as

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<sup>30</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 117.

<sup>31</sup> Schattschneider, *The Semi-Sovereign People: A Realist's View of Democracy in America*, 66.



caused or influenced by human actions and susceptible to human intervention; individuals must want to mobilize to affect change, or insist that their government representatives do so.<sup>32</sup> Towards this end, relevant actors compose stories in order to place an item on the agenda, and to assign responsibility for and control over it. These stories center on personal values, unfavorable comparisons, categorization, systematic indicators, focusing events, feedback, and humanitarian and security concerns. By making an item more visible, often by generating intense media coverage, these parties are expanding the scope of the conflict, making it more accessible, and increasing the likelihood that it will transcend traditional boundaries to unite various groups of people.

I have emphasized the role of political actors in composing these stories in an attempt to highlight their importance in setting the political agenda. After all, the government is the body with the greatest number of resources and the greatest potential to affect lasting change. At the same time, I do not want to understate the importance of the public agenda, or the role of NGOs and the media in placing items on it by mobilizing the public and elevating issues to authoritative positions on it. With regards to NGOs, they play an important role in what Rutherford deems CAS, generating attention for an issue and subsequently, placing it on the agenda.<sup>33</sup> In terms of the media, its ability to determine what people are thinking about and consequently, what is positioned on the agenda is increasing in our globalizing world with its rapid technological advances.<sup>34</sup>

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<sup>32</sup> Stone, "Causal Stories and the Formation of Policy Agendas," 281-82.

<sup>33</sup> Rutherford, "The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines," 78.

<sup>34</sup> Takeshita, "Exploring the Media's Roles in Defining Reality: From Issue-Agenda Setting to Attribute-Agenda Setting," 26.

Additionally, both of these actors engage in the other half of CAS, NAS. NGOs and the media not only affect what will be placed on the agenda, but how that issue will be perceived and construed once there. Using framing, schema, and priming, the well-honed ability of these agents to determine how society thinks about an issue is intimately related to how that issue is presented by a small number amongst us, political actors, as well as what policy alternatives will be generated by specialists to tackle it.<sup>35</sup>

Experts and bureaucrats in a given area are, for the most part, those who create policy alternatives. However, these individuals are not immune to outside influences. These men and women will put forth thousands of policies, and as was the case with agenda-setting, only a handful of these proposals will survive to the level of legitimate consideration. Generally speaking, alternatives that reach this level meet the following criteria: technical feasibility, value acceptability, tolerable cost, anticipated public acquiescence, and reasonable chance of receptivity among policymakers.<sup>36</sup> Viable alternatives that adhere to these standards are essential for ensuring that an item rises on the agenda and is appropriately addressed.

There is no set formula for determining how an item is placed on the agenda, or exactly what alternatives will be generated to respond to it once there. The synthesis of scholarly arguments presented above represents, insofar as is possible, the general parameters within which these processes normally take place. Agenda-setting and policy formation are extremely complex practices and accordingly, any explanation of them will

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<sup>35</sup> Rutherford, "The Evolving Arms Control Agenda: Implications of the Role of NGOs in Banning Antipersonnel Landmines," 78.

<sup>36</sup> Kingdon, *Agendas, Alternatives, and Public Policies*, 131-39.

be equally as elaborate. In the preceding pages, I have attempted to fuse the arguments of several of the most renowned scholars in the field of policymaking in order to put forth an explanation of how HIV/AIDS was placed on the American public and political agendas, how vertical initiatives became the primary response to this disease, and how public health more generally can be placed on these agendas. Revolutionizing the agenda and the policies produced to address these problems is the true challenge of global public health.

### **Setting an Example: The HIV/AIDS Pandemic**

Health has long held a place on agendas throughout the world. However, it was not until 1981 and the outbreak of HIV/AIDS in the United States that it began to rise to a position of primacy in the minds of civilians and policymakers alike. This disease, which affected both the developed and developing worlds, was not contained in the South, but has, and continues to threaten the North. Since its discovery, it has galvanized support for the global health movement, centered on its own prevention and treatment, premised in concerns over domestic health, national security, and humanitarian ideals.<sup>37</sup>

HIV/AIDS is exceptional in many ways. First and foremost, it has raised awareness of and generated funding for a number of other infectious diseases and global health more broadly; it reinvigorated an agenda item—health—that was wasting away in the dark corners of discarded and forgotten issues. Its capacity to garner national and international attention and to mobilize resources is well-documented, and has

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<sup>37</sup> Gregory K. Folkers and Anthony S. Fauci, “The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance,” *The Journal of the American Medical Association* 286, no. 4 (2001): 461.

demonstrated what can be accomplished when there is a strong and sustained commitment to a public health crisis.<sup>38</sup>

Moreover, as Peter Piot, the Executive Director of the United Nations AIDS program points out, this pandemic does not demonstrate signs of abating. (UNAIDS) This disease, which affects 33.2 million individuals worldwide and which killed 2.1 million people in 2007 alone, does not seem to be moving towards an epidemic equilibrium.<sup>39</sup> Coupled with the severity and longevity of its impact, its propensity for affecting young adults, and the social stigma stemming from the issues surrounding it—including sex, gender inequality, homosexuality, drug use, and prostitution—HIV/AIDS is a uniquely devastating disease.<sup>40</sup>

It was not in spite of the formidable challenges presented by HIV/AIDS, but because of them and the way in which they were placed on the American agendas that this disease came to be defined as a security threat by the US government, the UN Security Council, and international community more broadly, as well as a humanitarian issue by these same players, NGOs, celebrities, academics, philanthropists, and the public. HIV/AIDS has come to inspire both awe and fear throughout the world; many have placed it on the same level as nuclear war and global climate change.

HIV/AIDS captured the attention of both civilians and policymakers, was placed on both the public and political agendas, and generated a response—vertical initiatives—

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<sup>38</sup> Folkers and Fauci, “The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance,” 458.

<sup>39</sup> UNAIDS, “AIDS epidemic update: December 2007,” UNAIDS, [http://data.unaids.org/pub/EPISlides/2007/2007\\_epiupdate\\_en.pdf](http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf) (accessed February 5, 2008), 2.

<sup>40</sup> Peter Piot, speech given at the London School of Economics, “Why AIDS is exceptional,” February 8, 2005, London, England, 4.

that has come to act as the primary solution to all global health crises. HIV/AIDS is an extraordinary and catastrophic disease and it deserves to be addressed with fervor and funding. At the same time, it should not be allowed to distort and dismiss other global health issues lest we are all led to focus solely on this pandemic without regard to its precipitates.

John Gerring, an eminent social scientists asserts, “All knowledge is comparative ... New knowledge is categorizable only in terms of old knowledge; what we learn is contingent on what we already know.”<sup>41</sup> In the following pages, we will analyze, using the agenda-setting and policy formation framework laid out in this chapter, how HIV/AIDS was placed on the public agenda in the United States in order to learn how we can reset its counterparts in other countries with a new global health objective and a fresh set of policy alternatives to address it.

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<sup>41</sup> John Gerring, *Social Science Methodology: A Critical Framework* (New York, NY: Cambridge University Press, 2001), 157.

## CHAPTER FOUR: THE PUBLIC AGENDA

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### The American Public and AIDS

AIDS is not now, nor has it ever been, simply a disease to be contained and treated in the United States of America. Since its discovery in this country in 1981, it has been politicized, and its positioning on the American public agenda has been influenced as much by the social constructs surrounding it as by its dire medical consequences; homophobia, racism, and sexism have been as essential to the narrative of HIV/AIDS as any infectious agent or retrovirus.<sup>1</sup> In the following pages, I will present a brief, but comprehensive history of this disease in the US before examining the role of activists, celebrities, and the media—three of the most critical agents influencing the placement of this disease on the public agenda, in light of its background.

Activists in nearly every sector of society have looked to the successful placement of HIV/AIDS on both the public and political agendas in the US as an example after which they can model the promotion of their own causes and initiatives. As will be noted throughout this chapter, however, the journey of HIV/AIDS from obscurity to notoriety has not been as straightforward and uncomplicated as many have come to believe. Although the history of this disease in the US is oftentimes looked at as a favorable one given its position in contemporary society, it is illustrative of many of the shortcomings and weaknesses in our culture. In many ways, it is representative of one of this nation's greatest failures. The American public's response to HIV/AIDS has evolved considerably, but there is still much progress to be made.

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<sup>1</sup>Erik K. Lerner and Mary Ellen Hombs, *AIDS Crisis in America: A Reference Handbook* (Santa Barbara, CA: ABC-CLIO, 1998), 4.

## **The Coming of Age of AIDS in America**

The genesis of AIDS is a mystery to scientists, academics, and the general public. The birth of this infectious disease, which has come to devastate entire generations of men and women throughout the world, has been attributed to a variety of sources. Today, the most common theory on this subject asserts that HIV/AIDS originated spontaneously in Africa. This explanation, which is both sensible and sound, is a product of medical reasoning; many justifications for this illness are not. For instance, it has been speculated that AIDS was introduced in a government biological warfare laboratory, that it was injected into Africans along with widespread polio vaccinations during the 1950s, and that it began in Haiti. Still others attribute this disease to human behaviors. The Overload Theory, first introduced in 1981 to explain the prevalence of AIDS amongst gay men, argues that sexually active homosexuals have been infected with ample amounts of microorganisms as a result of their promiscuous lifestyles, which have caused their immune systems to collapse. Indeed, behavioral, environmental, racist, and theological explanations have been advanced as often as biological justifications to elucidate the onset of this disease.<sup>2</sup>

The confusion and controversy surrounding the origin of AIDS are indicative of the stigma and political overtones inherent in the public's perception of this disease, and the many issues stemming from its presence in American society. AIDS was first discovered in 1981, when a technician at the Center for Disease Control and Prevention (CDC) in Atlanta, Georgia noted an unusually high number of requests for pentamidine,

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<sup>2</sup> Douglas A. Feldman and Julia Wang Miller, *The AIDS Crisis: A Documentary History* (Westport, CT: Greenwood Press, 1998), 1-4.

a drug used to treat a rare infection—pneumocystis carinii pneumonia. (PCP) This observation led to the publishing of what would become the first report on AIDS on June 5, 1981 in *Morbidity and Mortality Weekly Report*. Entitled “Pneumocystis Pneumonia—Los Angeles,” it detailed the cases of five, young homosexual men in Los Angeles who had contracted this relatively obscure immunodeficient disorder, and urged doctors to be alert to these symptoms in their homosexual patients. This report on the presence of five PCP victims in Los Angeles was expanded upon just one month later, as the same journal put forth an article noting an extraordinarily high number of cases of Kaposi’s sarcoma (KS) in men who have sex with men (MSM) in New York, as well as additional instances of PCP in these individuals and others.<sup>3</sup> Rarely seen in healthy, robust young people, the rife of these illnesses in urban centers on either coast of the United States alerted physicians to what is today an established fact—these were not isolated events.

The domestic environment in which AIDS first appeared was one where most people, concerned with the country’s economic recession and the implications of the Cold War, had little time for public health issues; many believed the days of infectious diseases, killer plagues, and sweeping pandemics were long gone. This attitude, coupled with the initial outbreak of AIDS in gay men, led to the identification of this condition as Gay-Related Immune Deficiency Syndrome—a pejorative name for what then seemed to be a discriminatory disease. Along with “gay cancer” and “AIDS phobia,” this disease

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<sup>3</sup> “*Pneumocystis* Pneumonia - Los Angeles,” and “Kaposi’s Sarcoma and *Pneumocystis* Pneumonia Among Homosexual Men - New York and California,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller (Westport, CT: Greenwood Press, 1998), 16-17.



quickly became associated with one of the most marginalized groups in society—homosexuals—and thus, the response to this epidemic was greatly affected by social norms and personal prejudice.<sup>4</sup> It became apparent as early as 1982, however, that this disease was affecting individuals who did not fit into this category, including injecting drug users (IDU) and hemophiliacs. Thus, in 1982, the CDC christened this disease “Acquired Immunodeficiency Syndrome,” and published a preliminary definition of it, which has evolved and expanded over time with the addition of new information and discoveries, like that of the retrovirus that causes AIDS—HIV, as “the occurrence of biopsy-proven KS and/or biopsy—or culture—proven infections at least moderately predictive of cellular immune deficiency.”<sup>5</sup>

With a fledgling explanation to define the parameters of this mysterious condition called AIDS established, the CDC went on to declare the so-called high-risk groups for this disease on March 3, 1983. These factions, which would come to be known as the 4H’s of AIDS politics, included homosexuals, heroin users, Haitians, and hemophiliacs.<sup>6</sup> Although the CDC was persuaded to remove Haitians from this list in 1985 and admit it had mistakenly demonized them, the government’s identification of AIDS carriers as those communities who were already long discriminated against, particularly MSM and IDUs, only served to justify the biased attitudes propagated by the majority of the population towards those with AIDS; the articulation of the 4H-Club led to apathy and

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<sup>4</sup> Lawrence O. Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations* (Chapel Hill, NC: The University of North Carolina Press, 2004), xxi.

<sup>5</sup> Dale D. Chitwood, “United States,” in *HIV and AIDS: A Global View*, ed. Karen McElrath (Westport, CT: Greenwood Press, 2002), 254-255.

<sup>6</sup> Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Washington, D.C.: Georgetown University Press), 6.

antipathy on the part of mainstream America, not action. An epidemic that could have been contained and even reversed was instead allowed to multiply and fester as Americans allowed themselves to be divided by homophobia, racism, and sexism. So long as this disease was confined to homosexuals and drug users, it was convenient for most Americans to disregard it as a behavioral consequence, rather than a threatening epidemic. As it became clear that AIDS was not limited to these populations, still more discrimination was heaped upon these individuals and their families who became outcasts in society; many men and women suffering from AIDS lost their jobs, their insurance, and even their friends as a plague mentality rose up amongst the American people.<sup>7</sup> Considering this hostility, it is remarkable how much was accomplished during this time by dedicated researchers and activists.

In 1984, French virologist Luc Montagnier and American biomedical researcher Robert Gallo isolated the retrovirus that causes AIDS—the Human Immunodeficiency Virus.<sup>8</sup> It has since been determined that HIV, which is conveyed through the exchange of bodily fluids, primarily via the transfer of blood products, the congenital or perinatal transmission of fluids between mother and child during birth, or the interchange of fluids during vaginal and anal intercourse, initially manifests itself in flu-like symptoms within days or weeks of the infection.<sup>9</sup><sup>10</sup> Full antibody reaction to this acute retroviral syndrome is generally established within three to six months, at which point the disease is deemed chronic, and asymptomatic HIV sets in, which can last for a decade or more. During this

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<sup>7</sup> Chitwood, “United States,” in *HIV and AIDS: A Global View*, ed. Karen McElrath, 262.

<sup>8</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, 19.

<sup>9</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 5.

<sup>10</sup> Institute of Medicine of the National Academies, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* (Washington, D.C.: The National Academies Press, 2005), 40.

time, the disease gradually alters the body's immune system by reducing the number of CD4 cells in the peripheral circulation, which is what causes the immune system to deteriorate over time.<sup>11</sup>

The incubation period for HIV is significant; this is not a disease that kills quickly, but rather, one that debilitates and demeans the human body for many years preceding death. In 1987, the duration of this disease was further prolonged when Burroughs Wellcome pharmaceutical company introduced AZT, or zidovudine. AZT, a transcriptase inhibitor that works to prevent HIV from replicating at a specific point in its development process, was the first drug to be approved for use against HIV infection.<sup>12</sup> Though it was initially priced at \$10,000 annually per person, it was quickly adopted by thousands of individuals in the North seeking to cheat death. Nevertheless, both then and now, this drug, the most established response to HIV infection, may slow the progression of AIDS, but it does not increase survival rates.

The first decade of the AIDS epidemic in the United States can be counted among the darkest periods in this nation's history, as citizens and the government alike failed to respond to this epidemic of the "other." By the end of 1989, 151,079 cases of AIDS had been reported in the US and roughly 90,000 of those individuals, largely members of society's most disenfranchised populations, had perished.<sup>13</sup> The number of deaths that can be attributed to AIDS during this first, and most critical of decades, is reflective of one of the most reprehensible failures of our nation; Americans were largely silent,

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<sup>11</sup> Institute of Medicine of the National Academies, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, 41.

<sup>12</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 35-36.

<sup>13</sup> Chitwood, "United States," in *HIV and AIDS: A Global View*, ed. Karen McElrath, 257.

disinterested, and indifferent to AIDS, even as it claimed the lives of more men and women than the Vietnam War. In *And the Band Played on: Politics, People, and the AIDS Epidemic*, acclaimed author Randy Shilts, commenting on this country's response to AIDS during the ten years posterior to its discovery stated, "The numbers of AIDS cases measured the shame of the nation ... The United States, the one nation with the knowledge, the resources, and the institutions to respond to the epidemic, had failed. And it had failed because of ignorance and fear, prejudice and rejection."<sup>14</sup> Thousands of people died and entire groups of friends passed away, as lifestyle perceptions took precedence over pandemic implications. This decade, and the stigma and fear it bred, laid the foundation for the path that this disease has since tread along.

The 1990s witnessed the emergence of still more cases of AIDS and a steady increase in the body count attributed to this disease. By 1999, a total of 733,374 cases of AIDS were reported and approximately 40,000 new cases were emerging each year.<sup>15</sup> Indeed, this era saw the "second wave" of this epidemic in gay communities throughout the country, and particularly in San Francisco, as many men, desensitized by loss, numbed by grief, and resigned to the inevitability of their own deaths, once again began to engage in unsafe sexual practices. Said one homosexual man in San Francisco, "It makes you feel like what's the point ... Eventually you're going to get it, so why resist? We're surrounded."<sup>16</sup> Initially a product of overwhelming death, this complacency was fortified by the introduction of antiretroviral (ARV) drugs at the XI International

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<sup>14</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St. Martin's Press, 1987), 601.

<sup>15</sup> Chitwood, "United States," in *HIV and AIDS: A Global View*, ed. Karen McElrath, 257.

<sup>16</sup> Jane Gross, "Second Wave of AIDS Feared by Officials in San Francisco," in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 36.

Conference on AIDS held in Vancouver, Canada in 1996. Here, scientists introduced a combination therapy that combines a protease inhibitor, which targets the viral enzyme protease, such as Crixivan, Norvir, and Invirase, with two of the established drugs to fight AIDS including AZT. This three-drug cocktail, known as “highly active antiretroviral therapy (HAART),” lessens the impact of HIV on patients by decreasing their viral load counts from tens or hundreds of thousands to below 500, and by increasing their T4 cell counts, which bolsters their immune systems.<sup>17</sup>

HAART, which quickly became the standard of care for this disease, drastically reduced the morbidity and mortality associated with AIDS in the United States and other developed countries, and the visible scars of this disease on these nations quickly disappeared.<sup>18</sup> The introduction of HAART has changed the demographic of AIDS in the North, as people are living longer and prevalence is increasing but modestly as a result of persistent incidence at low levels.<sup>19</sup>

While the introduction of ARVs has benefited multitudes of men and women, and prolonged many lives, it has also contributed to a sense of contentedness in the developed world, where there is evidence that high-risk behaviors, which many organizations and public health officials sought to reduce in the 1980s, have rebounded with verve. Many individuals, in the wake of HAART and other new technologies, have come to view this disease as chronic, rather than fatal, and have responded accordingly. These attitudes,

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<sup>17</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 36.

<sup>18</sup> Gregory K. Folkers and Anthony S. Fauci, “The AIDS Research Model: Implications for Other Infectious Diseases of Global Health Importance,” *The Journal of the American Medical Association* 286, no. 4 (2001): 459.

<sup>19</sup> Peter Piot, Michael Bartos, Peter D. Ghys, Neff Walker, and Bernhard Schwartlander, “The Global Impact of HIV/AIDS,” *Nature* 410, no. 6831 (2001): 968.

according to authors Tony Barnett and Alan Whiteside, “may be the result of a false sense of security following a perception that HIV is now a ‘normal’ treatable disease. It might also be the result of a general fatigue in continuing with safe behaviors. Whatever the reasons, such trends are alarming and show the risks of complacency.”<sup>20</sup>

Additional problems that were born in the 1990s and which are coming of age in the present include the growth of drug-resistant strains of HIV, the bleak future for an AIDS vaccination, and the rise of HIV/AIDS among still more marginalized groups in society. In recent years, it has become apparent that racial and ethnic minorities are disproportionately affected by the HIV epidemic in the US; its primary targets are African-Americans and Hispanics.<sup>21</sup> Despite the fact that these men and women are representative of a minority of the population, they constitute the majority of new cases of both HIV and AIDS, as well as the number of AIDS-related deaths in the US.<sup>22</sup>

Today, the CDC reports six high-risk groups for HIV/AIDS including MSM, IDUs, men who have sex with men and inject drugs, persons with hemophilia and coagulation disorders, persons who engage in heterosexual contact, and persons in receipt of blood transfusions, blood components, and tissue.<sup>23</sup> Nevertheless, with MSM still representing the largest risk category, at 47 percent of all adult and adolescent cases in the United States, the number of IDU cases increasing, and the continuous shift of this disease towards new marginalized groups, it is apparent that HIV, in the most ironic of

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<sup>20</sup> Tony Barnett and Alan Whiteside, *AIDS in the Twenty-First Century: Disease and Globalization* (New York, NY: Palgrave Macmillan, 2002), 12.

<sup>21</sup> Chitwood, “United States,” in *HIV and AIDS: A Global View*, ed. Karen McElrath, 258.

<sup>22</sup> Institute of Medicine of the National Academies, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, 51.

<sup>23</sup> Chitwood, “United States,” in *HIV and AIDS: A Global View*, ed. Karen McElrath, 258.

circumstances, has, and will continue to affect the most vulnerable populations in society.<sup>24</sup>

Although basic knowledge and awareness of HIV/AIDS has increased among the general population, life-prolonging treatments have been introduced, legislation has been passed to assist men and women with AIDS, and thousands of organizations have sprung up throughout the country to address the needs of these individuals, HIV/AIDS continues to spread in the US.<sup>25</sup> Though this disease has ignited the public health movement in both a domestic and global context, and mobilized more resources than any other illness in history, its inability to resolve itself is indicative of the fact that not only can more be done to combat this disease and improve health more generally, but more must be done, both here in the US and abroad.

### **Bridging the Gap**

AIDS' position of primacy on both the public and political agendas today can be attributed to the highly effective campaigns of AIDS activists during the last twenty years. Mostly homosexual men at first, these individuals came together—as early as 1981—to offer support services to persons with AIDS (PWA), to educate the public and health professionals about AIDS and later, HIV, and to advocate for funding and legislation to assist and protect those infected by this disease.<sup>26</sup> Even as AIDS inspired fear and indifference in the general population, it gave rise to creativity and cohesion in the gay community. In *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled*

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<sup>24</sup> Chitwood, “United States,” in *HIV and AIDS: A Global View*, ed. Karen McElrath, 258.

<sup>25</sup> Ibid., 254.

<sup>26</sup> Ibid., 267.

*Expectations*, author Lawrence O. Gostin notes, “Never before had the gay community come together so openly and with such determination to expose the evils of stigma, discrimination, and underfunded research. Never before had vulnerable communities been so politically active and service oriented.”<sup>27</sup>

Indeed, these men united to introduce a new form of advocacy that would change the face of activism more generally, and influence advocates of breast cancer, Parkinson’s disease, and juvenile diabetes, as well as other activist groups outside the health realm.<sup>28</sup> AIDS activists adopted the classical approach to advocacy and innovated upon it, and in doing so, created a new model featuring direct action, self-empowerment, and self-education.<sup>29</sup> The gay community utilized these tools to raise awareness among themselves and the public, lobby for funding and attention in Washington, campaign for the development and equitable distribution of drugs, and organize community support organizations.

Early AIDS activists bridged the gap between the needs of those suffering from AIDS and the support and funding provided by the American government; it was initially a very wide chasm. In the early 1980s, these organizations were oftentimes composed of several individuals who took it upon themselves to deliver food, offer comfort and conversation, provide educational materials, and staff hotlines. With very few resources, agencies such as Gay Men’s Health Crisis (GMHC) and AIDS Project Los Angeles (APLA) performed miracles for thousands of men whose social deaths long preceded

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<sup>27</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxi.

<sup>28</sup> James F. Keenan, “Developments in Bioethics from the Perspective of HIV/AIDS,” *Cambridge Quarterly of Healthcare Ethics* 14, no. 4 (2005): 421.

<sup>29</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 6.



their physical demises in American society. Although these agencies were initially founded to provide for gay men suffering with AIDS, they quickly absorbed all high-risk populations. These AIDS advocacy, service, and funding groups garnered resources and generated awareness for this disease and the plight of those living with it by hosting celebrity galas, organizing walk-a-thons, and implementing initiatives such as the NAMES Project, or the AIDS Memorial Quilt Project.<sup>30</sup> These efforts provided the donations necessary to keep these organizations in the black, as government funding remained inconsistent at best.

Essentially, AIDS activists have been at the forefront of providing care and support for victims, educating the public, and lobbying the government for attention and resources. These groups have acted as guardian angels to those individuals living with AIDS, as well as enacted broad-based reforms in our society by protesting drug prices, advocating needle exchange programs, and encouraging sex education. The 1993 expansion of the CDC Surveillance Case Definition of AIDS, the reduction in the price of AZT by Burroughs Wellcome, the release of HIV-infected Haitians from Guantanamo Bay, and the Food and Drug Administration's (FDA) decision to expedite drug approval processes can all be ascribed to the efforts of AIDS activists.<sup>31</sup>

In fact, many of the accomplishments listed above can be attributed to the guerrilla theater tactics and protest demonstrations used by one of the most famous, and in many respects, infamous AIDS activism groups—the AIDS Coalition to Unleash Power. (ACT UP) Founded in 1987, this group is dedicated to confrontational political

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<sup>30</sup> Chitwood, "United States," in *HIV and AIDS: A Global View*, ed. Karen McElrath, 267-68.

<sup>31</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 26.

action to promote AIDS issues and awareness. Its unconventional strategies have summoned the attention of the public and officials alike. From its logo, a combination of the words SILENCE = DEATH and an inverted pink triangle, the symbol worn by homosexuals in Nazi concentration camps, to its affinity for street theater and eye-opening presentations, this group aims to shock the general population into action. Although it has alienated many Americans, ACT UP continues to be extremely effective.<sup>32</sup> Said leading AIDS activist and cofounder of ACT UP Larry Kramer, “ACT-UP is impolite, abrasive, rude—like the virus that is killing us ...”<sup>33</sup>

ACT UP, which grew rapidly in the late 1980s, has articulated its goals as follows: to speed up drug development, increase access to experimental drugs, and promote prevention strategies. Towards this end, it combines both nonviolent political action and civil disobedience. In his article for *Rolling Stone* magazine, journalist David Handleman observed, “Although ACT-UP personifies the age-old ideal of town meeting democracy, it is also thoroughly modern, shrewdly blending sixties style activism with the same tactics used by sophisticated political operatives, Spielbergian spectacle and media manipulation.”<sup>34</sup>

This organization’s most legendary protest is arguably its first one, which took place on March 24, 1987 in New York City. There, ACT UP/New York staged a major demonstration on Wall Street to protest the profiteering of major American pharmaceutical companies off drugs to combat HIV/AIDS. This organization engaged in

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<sup>32</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 176.

<sup>33</sup> Larry Kramer, “Ten Years of Plague: 110,530 Deaths ... and Counting,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 178.

<sup>34</sup> David Handleman, “ACT-UP in Anger,” *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 176.

outlandish behavior to attract the attention of executives, officials, the FDA, the NIH, the President of the United States, and the insurance industry. ACT UP brought props to this protest including an effigy of FDA Commissioner Frank Young, copies of an op-ed piece written by Larry Kramer in the *New York Times*, and various fact sheets proclaiming, “AIDS is everybody’s business now.”<sup>35</sup> On that windy March day, ACT UP disrupted business, had people arrested, demanded national attention, and was absolutely successful.<sup>36</sup> In response, the NIH decided to accelerate its procedures to review research proposals and the FDA agreed to speed up the approval process for experimental HIV drugs.<sup>37</sup> This is just one of many examples of how ACT UP has commanded consideration and resources. This organization may be offensive, insolent, and callous, but for all of its alienating strategies, it is, and has been, effective.

Like ACT UP, Gay Men’s Health Crisis has been essential to combating the AIDS epidemic in the United States of America. Unlike ACT UP, a group that is primarily known for its advocacy efforts, GMHC is renowned for its service programs. Established in 1981 by forty men, most of which had lost lovers and friends to AIDS, New York’s GMHC is one of the oldest and largest AIDS community-based organizations in the country.<sup>38</sup> What began as an effort to raise money for research and basic educational materials, it has become a multifaceted operation providing individual and group counseling, a hot line, case management and social services, legal

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<sup>35</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 19.

<sup>36</sup> *Ibid.*, 19.

<sup>37</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 23.

<sup>38</sup> Dennis Altman, *AIDS in the Mind of America* (Garden City, NY: Anchor Press/Doubleday, 1986), 84.

representation, free food, prevention programs, a newsletter, and a buddy program.<sup>39</sup>

This organization, which has largely operated on private donations, has come to address nearly every aspect of the HIV/AIDS care and treatment process, as well as compiled funds to be used for government lobbying and reform, both locally and nationally.

Without this organization, a model for similar groups throughout the country, the fates of thousands of AIDS victims in New York City, the hardest hit area in the United States relative to AIDS incidence and prevalence, would have been radically different.

Other notable organizations and activist groups include the APLA, the Whitman-Walker Clinic in Washington, D.C., the AIDS Action Council, the National Association of People with AIDS, and the Lambda Legal Defense and Education Fund. The significance of these organizations, and the debt owed them by our society, cannot be stated articulately or compellingly enough. Many of these groups were founded and began to function in response to a disease that no one knew anything about, at a time when people were dying in droves from an illness that demoralized and debilitated before it killed, when the government was silent in response to this epidemic, and when the American public was disparaging and disinterested at best. The men and women who organized these initiatives are responsible for caring for the victims of this disease at a time when no one else would, educating a nation, demanding a response, and mobilizing entire communities to rally against an epidemic that threatened to undermine the fabric of our society.

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<sup>39</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 163.

These groups continue to play an important role in generating awareness and promoting public education, and offering a supportive community to PWA. Stigmatized both at their onset and in contemporary society, these organizations provide hope for a future in which AIDS is considered in the same vein as any other disease, and in which all those who are infected can receive medical care, and be treated with the dignity and respect befitting their humanity.

### **The Many Faces of AIDS**

David Beckham, Angelina Jolie, and Melinda Gates. Today, these are the celebrities associated with AIDS—these are its representatives, the men and women who organize fundraisers and pose for photos. They are not, however, the faces of AIDS in any meaningful sense. Though these men and women, and others like them, do a great deal for this cause by speaking out on its behalf, they do not embody it. In many ways, the fact that prominent celebrities and philanthropists are aligning themselves with AIDS in spite of the fact that they have not contracted it is demonstrative of how far American society has come, from the stigma and discrimination that characterized the 1980s and much of the 1990s to today.

In order to understand how the public's perception of AIDS has evolved over time, from the marginalization and prejudice described in previous sections of this chapter to the general acceptance and awareness that represent the current national mood, it is important to study the original AIDS personalities including Rock Hudson, Ryan White, Elizabeth Glaser, and Earvin "Magic" Johnson. In "Overcoming Stigmatization: Social and Personal Implications of the Human Immunodeficiency Virus Diagnosis,"

author Beverly A. Hall argues, “Diseases are understood through the metaphors that describe [them]. For AIDS, ‘plague’ is the principal metaphor ... whereas cancer phobia taught us to fear polluting environments, AIDS has communicated fears about polluting people.”<sup>40</sup> The men and women listed above lessened the fears of the public by narrowing the distance between “us” and “them,” a critical distinction during the first decade of the AIDS epidemic. Hudson, White, Glaser, Johnson, and many more humanized this epidemic by putting a face to the statistics and a name to this disease.

Rock Hudson, the epitome of wholesome American masculinity, was diagnosed with AIDS on June 5, 1984. Nearly two months later, on July 25, when the public discovered that one of its leading men was both gay and suffering from AIDS, men and women across the country finally awoke to the reality of this epidemic and its implications for their lives.<sup>41</sup> This disclosure on the part of Hudson electrified the nation; Hudson was the first household name to contract and admit he was suffering from AIDS. Indeed, his announcement changed the character of this disease and generated both an unprecedented amount of attention and additional resources for it.<sup>42</sup> Said author Randy Shilts, “Rock Hudson riveted America’s attention upon this deadly new threat for the first time, and his diagnosis became a demarcation that would separate the history of America before AIDS from the history that came after.”<sup>43</sup> Hudson’s diagnosis provoked a great deal of media attention and public awareness, but his death on October 2, 1985 attracted

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<sup>40</sup> Beverly A. Hall, “Overcoming Stigmatization: Social and Personal Implications of the Human Immunodeficiency Virus Diagnosis,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 148.

<sup>41</sup> Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, 577-78.

<sup>42</sup> Mark C. Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs* (Washington, D.C.: Georgetown University Press, 2001), 55.

<sup>43</sup> Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, xxi.

still more publicity for AIDS. By this cold day in early fall, the word AIDS was a familiar one in nearly every household in America. At the same time, it took the death of a movie star to make this threat palpable and this topic suitable for discussion in the general American population.<sup>44</sup>

If Hudson's announcement did not raise enough controversy in American society on its own, its nearly simultaneous coverage alongside the plight of Ryan White certainly did. The stories of this man and this boy altered the significance of AIDS for both American newspeople and the general population.<sup>45</sup> White, a thirteen-year-old hemophiliac living in Kokomo, Indiana, contracted AIDS from contaminated blood products. His case became famous when he was expelled from his local public school because of his illness. White responded by challenging his expulsion in court; he won the right to attend school. Nevertheless, after returning to his hometown where he continued to face harassment, his family moved, at the request of the town of Cicero, Indiana, to avoid further discrimination.<sup>46</sup>

Ryan White is the most famous of the many schoolchildren who contracted HIV/AIDS during its first decade in America. White, and those like him, presented unique challenges to public officials seeking to allay the fears of worried parents and teachers that AIDS could be contracted through casual contact.<sup>47</sup> Though White was allowed back into the classroom, many children with AIDS were not. On April 8, 1990, Ryan White died at the tender age of eighteen. His legacy, however, lives on in both the

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<sup>44</sup> Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, xxi.

<sup>45</sup> Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs*, 56.

<sup>46</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 113.

<sup>47</sup> Chitwood, "United States," in *HIV and AIDS: A Global View*, ed. Karen McElrath, 264.

Ryan White Comprehensive AIDS Resources Emergency Act, which will be discussed later in this text, and his memorial as an “Educator for Life,” as part of the NAMES Project.<sup>48</sup> His efforts to speak out against the disease that was killing him and so many others, when combined with the death of Hudson, led to a shift in the conceptualization of AIDS in the United States.<sup>49</sup> Essentially, the deaths of Hudson, a movie star, and White, a child, democratized this disease in America.

Hudson and White were not, however, alone in their endeavors. Elizabeth Glaser was, and continues to be, an important figure in the history of AIDS despite her death fourteen years ago. Glaser, the wife of celebrity Paul Glaser—best known for his role as Starsky in *Starsky and Hutch*, contracted AIDS from a blood transfusion she received shortly after giving birth to her daughter, Ariel, in 1981. Unknowingly, she passed this disease on to both her daughter, through breast milk, and her son, Jake, who contracted the disease in utero. After discovering that she and her children were HIV-positive, Elizabeth dedicated her life to finding treatment for her children, only to learn that no drugs had yet been prescribed to combat this infection in newborns and adolescents. As a result, Ariel died in 1988. Devastated by the death of her daughter, and the seemingly inevitable demise of her young son, Glaser approached two of her closest friends, and together, they established the Elizabeth Glaser Pediatric AIDS Foundation to raise money for children suffering with HIV/AIDS—a neglected population in a sea of marginalized communities.<sup>50</sup> This foundation, the largest of its kind in America today, is

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<sup>48</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 92.

<sup>49</sup> Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs*, 56-57.

<sup>50</sup> Elizabeth Glaser Pediatric AIDS Foundation, “Foundation History,” Elizabeth Glaser Pediatric AIDS Foundation, [http://www.pedaids.org/AboutUs/FoundationHistory.aspx#f\\_story](http://www.pedaids.org/AboutUs/FoundationHistory.aspx#f_story) (accessed March 21, 2008).



representative of Elizabeth's legacy as one of the first female faces of AIDS, but also, as one of the earliest individuals to demonstrate the effects of this epidemic on America's children. As a result of her efforts, her son Jake is still alive today. An American sweetheart, Elizabeth Glaser made this disease a tangible one for housewives and working women alike in neighborhoods throughout the US.

Earvin "Magic" Johnson is the Rock Hudson for today's youth. A professional basketball player with a variety of endorsements and television commercials, Johnson announced he was HIV-positive in November 1991 after having unprotected sex with a woman.<sup>51</sup> A successful, heterosexual athlete, a non-drug user, and a role model for young people, Johnson rejuvenated publicity and attention for HIV/AIDS and demonstrated to straight men across America that they were not infallible.<sup>52</sup> Johnson, who has since devoted himself to AIDS education and awareness, was named to the National Commission on AIDS by President George Herbert Walker Bush, before resigning in protest of the administration's inaction with regards to this epidemic.<sup>53</sup> Alongside Arthur Ashe, Johnson is one of the principal black representatives of AIDS in America, and his role as an African-American with this disease is increasingly important, as this population is one of the most vulnerable in contemporary society.

A white, gay male; a child with hemophilia; a young woman and her children; an African-American, heterosexual male; anonymous, these four individuals embody the diversity of the AIDS epidemic and the thousands of men, women, and children living

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<sup>51</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 87.

<sup>52</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 27.

<sup>53</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 87.

with this disease throughout the United States. When identified, however, Rock Hudson, Ryan White, Elizabeth Glaser, and Magic Johnson are four individuals who stood for all those PWA who could not, and who used their influence to tell a story to the American people about the epidemic sweeping across the country. These individuals brought this disease out of clinics, clubs, hospitals, and urban centers and into the living rooms of all Americans. These four people, several of the most prominent and influential faces of AIDS, democratized this disease, and forced US citizens to recognize the nightmare living alongside the American dream.

### **AIDS in the Media and Public Mind**

The American media both structures the public consciousness and reflects the national mood; it is both a cause and effect of the preferences and beliefs of mainstream America. In no other epic tale is the media's power and influence over society as apparent as it is when considering the AIDS epidemic in this country. With over 41,000 news stories printed and broadcast about this disease between 1981 and 2002, the evolution of the tone of these stories from apathy and discrimination, to fear and panic, to hesitant acceptance and general awareness reflects the predominant changes in public perceptions more broadly.<sup>54</sup> HIV/AIDS is a story that typifies much more than science and medicine; it is a narrative about arts, culture, taboo, lifestyles, business, religion, celebrities, sexuality, and

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<sup>54</sup> Mollyann Brodie, Elizabeth Hamel, Lee Ann Brady, Jennifer Kates, Drew E. Altman, "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," *Columbia Journalism Review*, Supplement: March/April 2004, 2. The study from which this information has been obtained was based on a sample of more than 9,000 news stories from US print and broadcast outlets including four major national newspapers, three major regional newspapers in areas devastated by HIV/AIDS, and three major network news programs, gathered between 1981 and 2002.

politics, and it has been considered in light of all of these topics since its debut in 1981.<sup>55</sup>

AIDS is a story that centers on the most intimate of issues in the private lives of men and women. Accordingly, this disease has elicited a wealth of controversy and has brought out both the best and worst in Americans and US culture. Media coverage has been heavily influenced by personal prejudices and assumptions. Although coverage has become more tolerant over time, this disease has never been a priority for newsmakers. Surges in media reportage, few and far between, are indicative not of inadequate amounts of funding, accumulating body counts, or the plights of minorities as they are increasingly infected by HIV/AIDS, but rather, correspond to times when AIDS became personal, and threatening, for journalists and their readers. Author James Kinsella, in *Covering the Plague: AIDS and the American Media*, maintains:

The three peaks of AIDS reportage, in fact, correlate to events that suggest such a movement, or a way to contain it. In 1983, fear of widespread and rampant infection was triggered by rumors that AIDS could be spread by simple household contact. In 1985, actor Rock Hudson's death spurred a wave of interest because it appeared as though the disease was affecting even all-American types. And in early 1987, the discussion around containing the threat with widespread testing for the AIDS virus caused another explosion in news coverage.<sup>56</sup>

Three-fourths of US citizens receive the majority of their information about AIDS from the media—television, newspapers, and radio, even as domestic coverage of AIDS, and particularly those stories with educational components, declines. With four in ten Americans under the impression that HIV/AIDS can be transmitted though kissing, it is clear that the inadequacies of media coverage need to be addressed.<sup>57</sup> The media is

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<sup>55</sup> Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," 1.

<sup>56</sup> James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, NJ: Rutgers University Press, 1989), 4.

<sup>57</sup> Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," 1, 7.

responsible for acting as a public guardian and educator; it has failed with respect to this epidemic. It is high time the media devotes more time to stories at the heart of this disease in the US, rather than those that skim the surface of comfortable American conversation.

An analysis of the earliest years of media coverage of this epidemic demonstrates that while the American media must still affect a variety of changes, it has made quite a bit of progress since the outbreak of AIDS almost three decades ago. After the publication of the first stories on AIDS in the medical journal *Morbidity and Mortality Weekly* in 1981, this story was quickly picked up by similar medical and health publications as well as gay newspapers and magazines across America. It is important to note that until 1983, only the medical and gay communities were aware of this illness and the health crisis it was precipitating. Gay newspapers like the *New York Native* pioneered coverage of this epidemic while the national media largely ignored it. During this time, gay activists were responsible for caring for the victims of AIDS, as well as educating the gay, lesbian, bisexual, and transgender (GLBT) community about the disease pulsing through their ranks. National publications, indifferent to gay-related issues and politics, and particularly repulsed by stories of gay sexuality, failed to report this topic to the general public, and in doing so, acted as an accomplice to this devastating disease.

In April 1983, GMHC sponsored a fundraiser in an 18,000 seat auditorium in New York City entitled, “Night at the Circus.” Although this event was largely attended by members of the GLBT community, it marks the turning point of the AIDS epidemic with regards to national media coverage. Before that night, few people outside of the

aforementioned community had ever heard of AIDS, but by May 1983, newspapers, magazines, television and radio stations were all reporting on AIDS as if it had just been discovered.<sup>58</sup>

This publicity generated fear, confusion, and panic, but most importantly, these early stories forever associated this disease with homosexuality, a belief that has been difficult to dispel despite the discovery of other affected groups. Portrayed as intrinsically gay, early headlines included “Being Gay Is a Health Hazard,” “Gay Plague Has Arrived in Canada,” and “Male homosexuals aren’t so gay anymore.”<sup>59</sup> This bias in terms of the media, arguably the only source from which Americans were receiving news of this epidemic, led to a great deal of discrimination against the gay community. Fueled by sensationalism and exaggeration, AIDS was used by the media to appeal to medical interest, voyeurism, and fear—reportage of alternative lifestyles, and particularly those being plagued by an infectious disease, captured the public’s attention, albeit briefly.<sup>60</sup> After the initial burst of coverage, stories on AIDS in the national media were sporadic and perfunctory at best, often falling into the science section of publications.<sup>61</sup> Be that as it may, 1983 marks the year in which the general public became aware of this disease. Although it was thought to be limited to the gay community, and though there was little factual information circulating among the population, AIDS had entered the public consciousness, and there it has remained.

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<sup>58</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 22.

<sup>59</sup> Altman, *AIDS in the Mind of America*, 17.

<sup>60</sup> Ibid., 19-20.

<sup>61</sup> Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, 267.

The second landmark event in the history of AIDS and the media occurred in 1985. It was not until this year, and approximately 12,000 deaths from AIDS later that most American media outlets began to cover this disease with relative consistency.<sup>62</sup> 1985 was the year in which actor Rock Hudson died, and it was his demise and the ample amounts of attention it received that made AIDS a reality for the majority of Americans; the belief that that this disease was limited to the most marginalized in our society was dispelled at long last. For most Americans, the recognition of AIDS did not stem from direct loss or a personal connection to this disease, but from fear of contagion and the infections of various celebrities. Rock Hudson, Ryan White, Elizabeth Glaser, and Magic Johnson not only inspired vast amounts of media coverage, but also demonstrated to Americans that this disease was not that of the “other.” Although publicity surrounding children and hemophiliacs was important as a means of focusing attention on HIV/AIDS, rather than the lifestyles of its victims, the media’s early equation of AIDS with homosexuality led many in America to blame the gay community for infecting “innocent victims” with the gay plague.<sup>63</sup>

A product of fear, fascination, and the deaths of a number of celebrities to this damning disease, AIDS coverage in the media rose steadily throughout the 1980s, peaking at over 5,000 stories in 1987. Reportage has declined since then; there were just 1,000 stories on HIV/AIDS in 2002.<sup>64</sup> Minor peaks in coverage between 1987 and today have stemmed from publicity surrounding Magic Johnson’s announcement that he was

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<sup>62</sup> Kinsella, *Covering the Plague: AIDS and the American Media*, 2.

<sup>63</sup> Altman, *AIDS in the Mind of America*, 2, 25.

<sup>64</sup> Brodie et al., “AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002,” 2.

HIV-positive in 1991, the introduction of ARVs and HAART in 1996, coverage of international conferences on AIDS, and more recently, the global threat of this pandemic.<sup>65</sup> A noteworthy trend since 1987 is the shift in stories on AIDS away from a focus on gay men and other affected subgroups to the portrayal of the face of AIDS in most news stories as a healthcare professional.<sup>66</sup> This is a travesty and a liability as the majority of new HIV infections, and the number of deaths accruing from AIDS, are greatest among minority populations, who are represented in less than 3 percent of stories on HIV/AIDS.<sup>67</sup>

The media has facilitated the popularization of this disease. Although it initially encouraged a discriminatory view of HIV/AIDS, and despite the fact that it continues to avoid reporting the most pressing issues stemming from this disease, the media has contributed to the placement of HIV/AIDS in the public mind and on the public agenda.

AIDS has by now become a staple item of the news and a part of American consciousness, and much of the credit lies with the journalists who dared to use their own experience and outrage as the lead into a major story. At the same time, at least some of the blame for the ravages of AIDS in America must lie with members of the media who refused to believe that the deaths of gay men and drug addicts were worth reporting.<sup>68</sup>

The American media, like so many other groups in society, politicized this disease and encouraged others to do the same. One of the most influential outlets in this country, the media did not serve the public when it was most needed; its negligence will forever tarnish the image of this channel of information in America.

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<sup>65</sup> Ibid., 2.

<sup>66</sup> Ibid., 5.

<sup>67</sup> Ibid., 5-7.

<sup>68</sup> Kinsella, *Covering the Plague: AIDS and the American Media*, 1.

## **From the Public to Political Agenda: The Journey of HIV/AIDS**

The positioning of AIDS on the American public agenda, *the list of subjects or problems that are accorded saliency in the media and people's consciousness, and which, consequently, have captured the attention of government officials and those closely associated with them including bureaucrats, specialists, and various governmental and non-governmental organizations*, has been shrouded in stigma, homophobia, racism, and discrimination, and its placement can be attributed as much to terror and revulsion as the presence of a monumental health crisis. AIDS has never been simply a disease in the public mind; it has been, and continues to be, a statement—of values, lifestyle choices, and politics. Nevertheless, for right or wrong, HIV/AIDS has been placed on the American public agenda as a result of the efforts of dedicated activists and organizations which not only educated a nation, but prevented this epidemic from swelling to still greater dimensions, the infections of several celebrities and everyday citizens who had the courage to confront and combat this disease before an entire nation, and the coverage, both good and bad, of the American media.

The same ignominy and condemnation surrounding AIDS bred in the public sector went on to infect the political realm of society. Indeed, the placement of this disease on the American political agenda is party to the same discriminatory and biased conditions that were nurtured by the public sector during the early years of this disease; many of the same agents and occurrences that heavily influenced the public agenda also impacted the formation of the political agenda. In the following chapter, we will examine the circumstances surrounding the positioning of HIV/AIDS on the American political



agenda and analyze the role of the public in this process. “No aspect of life is more fundamental than health, both as a defining quality of personal and national vitality and, for the United States, as a vehicle for the dreams of liberty and opportunity codified in our founding documents.”<sup>69</sup> Subsequent pages will evaluate the response of the US government to the HIV/AIDS epidemic and determine whether or not it has adequately protected the most indispensable of civil liberties for its citizens—their health.

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<sup>69</sup> Michael McGinnis, “Infectious Diseases,” in *Critical Issues in Global Health*, ed. C. Everett Koop, Clarence E. Pearson, and M. Roy Schwarz (San Francisco, CA: Jossey-Bass, 2001), 81.

## **CHAPTER FIVE : THE POLITICAL AGENDA**

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### **The Positioning of AIDS on the American Political Agenda**

The relationship between the public and political agendas is mutually transformative.

The positioning of an item on the former is oftentimes indicative of its placement on the political agenda shortly thereafter. In the democratic society in which we live, while the public's interest in an issue does not necessitate the attention of government officials and the allocation of resources by these parties, it commonly generates government action, or at the very least, its consideration. At the same time, those items that capture and hold the attention of political actors, and the way in which they are addressed by these agents frequently determines the shape of the public response to these issues in terms of their significance, implications, and position in the public consciousness more generally.

Indeed, even as the government is influenced by the public agenda, political actors are affecting changes with ramifications that impact society at large.

The positioning of HIV/AIDS on the American political agenda was subject to the same stigma and silence that was witnessed in the placement of this fatal illness on the public agenda. The reaction of the government, and particularly the presidency, to this epidemic has evolved substantially over time, and was initially quite disappointing to PWA and those advocating on their behalf. Though many organizations and private agencies undertook heroic endeavors to provide for victims of AIDS and their families, and to educate the general public about this disease, their efforts could not replace the active participation of the government in responding to this crisis. In a speech given at

the London School of Economics entitled, “Why AIDS is Exceptional,” Peter Piot, Executive Director of UNAIDS and Under-Secretary General of the UN argued:

The role of governments in initiating, leading and coordinating the response is paramount. We have never seen a single nation reverse its epidemic without the strong leadership of a President or Prime Minister, who looks at the numbers and evidence, admits the danger, and delivers the right kinds of response. No partnership, no NGO, no business can replace this role. Only governments have the mandate to direct the national policy, national resources, and national leadership that is the foundation of a response to this epidemic at a scale that will actually make a difference.<sup>1</sup>

The US government long lacked the political courage to address this disease and counter its consequences. Surrounded by controversy, stigma, and discrimination, AIDS was a political nightmare, and one that few politicians were willing to confront. Though this disease has come to be the dominant force guiding the global public health campaign, its journey into the minds, hearts, and pockets of the most powerful political players in the world was not an easy one. Accordingly, an analysis of the trials and tribulations encountered by this disease and those promoting it to an authoritative position on the political agenda in the US, one of the most influential states in the world and that which has spearheaded the fight against HIV/AIDS in the South, is necessary to understand those tactics which led this disease to be placed on the political agenda, and which can be applied to other campaigns to elicit a similar governmental response.

The positioning of HIV/AIDS on the American political agenda can be divided into three periods, beginning in 1981 and carrying on into the present.<sup>2</sup> The first period, lasting from 1981 to 1987, is considered to be the darkest in the history of this epidemic;

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<sup>1</sup> Peter Piot, speech given at the London School of Economics, “Why AIDS is exceptional,” February 8, 2005, London, England, 12.

<sup>2</sup> Lawrence O. Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations* (Chapel Hill, NC: The University of North Carolina Press, 2004), xxiv.

it was a time of ignorance, indifference, and silence. A product of the depressed regard for the marginalized populations targeted by HIV/AIDS, government officials fell prey to the same prejudiced and bigoted attitudes as the public, and largely ignored this disease as it murdered multitudes of homosexual men and drug users throughout the United States. This disease, which gave rise to concerns over sexuality, lifestyle, values, and death, was not welcomed by the conservative Reagan administration. This president, sworn into office the same year as the outbreak of HIV/AIDS, failed to mention this disease even once before 1986—five years and nearly 21,000 deaths later. The political climate into which this disease was born was inhospitable to HIV/AIDS and its implications.

In the wake of the increasing effects of this disease on heterosexuals, politicians were able to reframe HIV/AIDS and push legislation through Congress to support PWA during the second era of this epidemic, lasting from 1987 to 1997. The additional funding made available by these bills, the acceleration of the transmission of this disease, and the accruing body counts attributed to HIV/AIDS, led federal agencies to become more active in countering this illness. Though Congress and various federal divisions made a great deal of progress in confronting this disease, the executive branch of the government, and especially President George H.W. Bush, remained silent. Though many had high hopes for the inauguration of President Bill Clinton, he too was fairly dismissive of this epidemic and its consequences for American society.

It was not until the third and final period, lasting from 1997 until today, that the United States Commander-in-Chief began to play a more active role in battling

HIV/AIDS. This interest, and the progress that has stemmed from it, has not been the product of domestic complacency or the US's status as one of the countries with largest number of HIV infections in the world, but rather, of the declaration of the US government of AIDS as a national security threat in 2000. This designation elicited an unprecedented reaction from this nation's head of state. The classification of AIDS as a national security threat led the US government to pour billions of dollars into combating this disease in the developing world. In light of its new title, the US government has finally recognized the magnitude of the HIV/AIDS pandemic and its effects in terms of social capital, population structure, and economic growth. Indeed, Washington has come realize that these deleterious consequences are only a small sample of that which is to come given the rapid transmission of this disease and its considerable gestational period.

As has been noted in previous chapters, the political agenda includes those preeminent issues that have moved into position for some sort of serious authoritative decision by the state.<sup>3</sup> In the following pages, each of the three periods of HIV/AIDS will be evaluated in an attempt to understand how this disease was transformed from an item of political antipathy in the US, to that which has come to be the number one health priority on the political agenda in this country.

### **1981-1987: Silence, Indifference and Ignorance**

This first, and most devastating period of HIV/AIDS in America, is that which saw the birth of this disease and its growth from a fatal, but containable illness, into a pandemic

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<sup>3</sup> John W. Kingdon, *Agendas, Alternatives, and Public Policies* (New York, NY: HarperCollins College Publishers, 1995), 142.

of global proportions.<sup>4</sup> It was during this time that Reaganism, those policies that strengthen the military while simultaneously weakening the role of the state in protecting social welfare and civil rights, dominated the American political agenda.<sup>5</sup> The Reagan administration, determined to adhere to this strategy, had little time for a disease that primarily affected the 4H-Club; these men and women did not pose a political threat to this party, which felt it would garner more support from its conservative base by ignoring these groups than by supporting them. The government largely dismissed this outbreak and allowed private agencies such as the APLA to care for patients and educate members of their communities, even as thousands passed away and still more were infected by this unforgiving illness.

Social prejudice and moral judgment are of paramount importance when considering the government's initial response to this disease. It first began to take notice of HIV/AIDS following the GMHC fundraiser in NYC, but it remained passive in responding to this epidemic for several years thereafter. This is evidenced by the activity, or rather, inactivity, of the government agencies responsible for AIDS-related work. These departments largely fall within the purview of the Department of Health and Human Services, and include the CDC, NIH, and FDA. The CDC, in particular, was overworked and underfunded during this period. Indeed, two years after the onset of AIDS, the Reagan administration had yet to request any funding for AIDS research, and

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<sup>4</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxiv. Gostin argues that the history of the AIDS epidemic in the US can be divided into three phases: "Denial, Blame, and Punishment, 1981-1987; Engagement and Mobilization, 1987-1997; and Complacency, Injustice, and Unfulfilled Expectations, 1997-present." While I find these timeframes to be both useful and accurate, the titles of Gostin's divisions do not reflect my own estimation of these periods.

<sup>5</sup> Dennis Altman, *AIDS in the Mind of America* (Garden City, NY: Anchor Press/Doubleday, 1986), 27.

although Congress made its first appropriation of resources for AIDS in October 1982, its distribution was more an effort to silence activists and public health officials than to affect any lasting change. For example, the CDC initially spent just \$2 million USD to study HIV/AIDS as opposed to the \$9 million USD it spent on the outbreak of Legionnaire's Disease and the \$10 million USD it spent in the first two weeks of the Tylenol scare in 1982.<sup>67</sup>

Throughout these early years, as HIV/AIDS appeared to be confined to homosexuals and drug users, the government disregarded this disease as self-inflicted and the product of immoral and destructive behaviors.<sup>8</sup> Policymakers, like the American public, responded to this disease in accordance with their sense of vulnerability to HIV/AIDS, which was extremely limited during this time.<sup>9</sup> This feeling of detachment is the reason why government officials paid so little attention to the outbreak of this disease. In spite of this emerging health crisis, an embarrassing topic for most Americans, it was considered acceptable, and even preferable, for President Reagan to ignore AIDS in the 1984 presidential election. Presidential leadership determines issues of national importance and the manner in which items will be addressed on the political agenda; the Reagan administration's blatant disregard for the AIDS epidemic and those affected by it

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<sup>6</sup> "Forcing Government to Act," in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller (Westport, CT: Greenwood Press, 1998), 170.

<sup>7</sup> Erik K. Lerner and Mary Ellen Hombs, *AIDS Crisis in America: A Reference Handbook* (Santa Barbara, CA: ABC-CLIO, 1998), 116.

<sup>8</sup> Dale D. Chitwood, "United States," in *HIV and AIDS: A Global View*, ed. Karen McElrath (Westport, CT: Greenwood Press, 2002), 262.

<sup>9</sup> Linda J. Kerley, "The Escalating Health Care Cost of AIDS: Who Will Pay?," in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 45.

was irresponsible and alludes to its prioritization of political support over public health.<sup>1011</sup>

It was not until 1985, and the death of Rock Hudson—a personal friend of President Reagan—that the American Head of State began to take an active interest in this disease. Indeed, the death of this Hollywood star not only generated an unprecedented amount of attention for HIV/AIDS, but also convinced the most powerful political actor in America to consider this epidemic and recognize the severity of its impact.<sup>12</sup> Rock Hudson’s death, when combined with the efforts of Ryan White, Elizabeth Glaser, Kimberly Bergalis, and other HIV-infected individuals, demonstrated to policymakers that this disease was not limited to the most marginalized members of our society, but was capable of infecting any American. It was this evidence, of the growing heterosexual transmission of AIDS, that ultimately persuaded government officials to take action; huge expenditures of funds, primarily dedicated towards HIV testing, surveillance studies, and clinical research, were allocated as a result of this newfound concern.<sup>13</sup> Led by Representative Henry Waxman of Los Angeles and Representative Ted Weiss of New York City, AIDS was placed on the political agenda. Although these policymakers were obligated to frame this disease in terms of its effects on heterosexuals, women, children, and healthcare professionals in order to garner support from conservative members of Congress and the American public more generally, this disease

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<sup>10</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 169.

<sup>11</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 170.

<sup>12</sup> Kathy Holub, “Rock Hudson Confirms He Has AIDS,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 26.

<sup>13</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 160.



began to elicit the attention of the US government. President Reagan, so long silent on this topic, finally uttered the word “AIDS” in public in 1986 and delivered his first major speech addressing this topic at the Philadelphia College of Physicians in 1987, after the diagnosis of 36,058 Americans from this disease and the deaths of 28,049 more from it.<sup>14</sup> Moreover, he appointed a National AIDS Commission. Although this body was devoid of physicians who had treated AIDS patients and included those who opposed AIDS education, it nevertheless demonstrated a novel effort on the part of the US government.<sup>15</sup>

The legitimization of HIV/AIDS in the eyes of policymakers, a product of its effects on heterosexuals, may have led to its positioning on the political agenda, however, this placement did not come without a price. Even as the government slowly began to consider this disease and address its implications, AIDS hysteria swept across the nation, fueled by fear, sensationalism, and the impassioned rhetoric of conservatives such as Pat Buchanan, Jesse Helms, Jerry Falwell, Gary Bauer, Pat Robertson, and Ronald Goodwin. These individuals used AIDS as a justification to promote their anti-gay bigotry and right-wing ideals, and they spoke out strongly and frequently against government involvement with this disease.<sup>16</sup> Moreover, these social and political leaders not only facilitated governmental inaction, but encouraged discrimination against PWA by both other PWA and the American public, by dividing these individuals into those who were guilty and those who were innocent—those who contracted HIV by means of sex or drugs

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<sup>14</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St. Martin's Press, 1987), 596.

<sup>15</sup> Lou Cannon, *President Reagan: The Role of a Lifetime*, in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 172.

<sup>16</sup> Greg Behrman, *The Invisible People: How the U.S. Has Slept Through the Global AIDS Pandemic, the Greatest Humanitarian Catastrophe of Our Time* (New York, NY: Free Press, 2004), 27.

versus those who contracted this disease perinatally or through a blood transfusion.<sup>17</sup> In what can be considered a relatively moderate article, author Ronald Goodwin writes, “Homosexuals and their practices can threaten our lives, our children, can influence whether or not we have elective surgery, eat in a certain restaurant, visit a given city or take up a certain profession or career—all because a tiny minority flaunts its lifestyle and demands that an entire nation tolerates its diseases ...”<sup>18</sup>

It was this type of discriminatory language that provoked and sustained the panic experienced by many in mainstream America, and encouraged the rise of public referendums such as Ballot Proposition 64 in California, which sought to quarantine all PWA in this state for the remainder of their lives. Sponsored by a Lyndon LaRouche Organization identified as PANIC—the Prevent AIDS Now Initiative Committee—this referendum failed, however, it did garner the 683,000 signatures necessary to place it on the ballot in the first place.<sup>19</sup> On the federal level, this fear of HIV/AIDS manifested itself in the actions of several federal agencies including the Department of Defense, which began to screen all of its recruits and reject those who were HIV-positive, and the State Department, which began to screen immigrants and deny those who were HIV-positive admission into the US on the grounds that they were infected with a contagious disease.<sup>20</sup>

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<sup>17</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxv.

<sup>18</sup> Ronald S. Goodwin, “AIDS: A Moral and Political Time Bomb,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 25.

<sup>19</sup> Charles Petit, “California to Vote on AIDS Proposition,” in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 27.

<sup>20</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxv.

It is important to note that although many government officials at the local, state, and federal levels exhibited prejudice towards PWA during the 1980s, there were men and women inside the government who sought to counter the discriminatory rhetoric and actions of their colleagues. US Surgeon General Dr. C. Everett Koop, a staunch opponent of abortion, was also a surprising and invaluable champion of AIDS engagement and education within the Reagan administration.<sup>21</sup> He not only encouraged the recognition of HIV/AIDS as a public health crisis, rather than a political issue, but democratized fear of this disease by propagating the notion that AIDS was a threat to every American, including those living in white, middle-class suburbia.<sup>22</sup> In a report published in October 1986 Koop wrote, “We are fighting a disease, not people ... The country must face this epidemic as a unified society. We must prevent the spread of AIDS while at the same time preserving our humanity and intimacy.”<sup>23</sup>

The first seven years of the AIDS epidemic in America were characterized by political apathy and inaction as government officials, and particularly the president, dismissed this disease and its effects on society as limited to MSM and IDUs. It took the transition of this disease from homosexual to heterosexual to ignite government action and generate funding for this disease. This reaction, however, was far too little, and far too late, as conservative authorities encouraged AIDS hysteria, and the stigma surrounding this disease intensified. Many people blame President Reagan, who entered office the same year as HIV/AIDS was discovered in the US, for its epidemic proportions

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<sup>21</sup> Behrman, *The Invisible People: How the U.S. Has Slept Through the Global AIDS Pandemic, the Greatest Humanitarian Catastrophe of Our Time*, 27.

<sup>22</sup> James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, NJ: Rutgers University Press, 1989), 4.

<sup>23</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 184.

in this country today. In *And the Band Played on: Politics, People, and the AIDS Epidemic*, author and activist Randy Shilts noted a sentiment held by many at the end of this period, “Ronald Reagan would be remembered in history books for one thing beyond all else: He was the man who had let AIDS rage through America, the leader of the government that when challenged to action had placed politics above the health of the American people.”<sup>24</sup> In the end, little can be said of the political will to combat this disease during its initial phase. This was a time of silence, indifference, and ignorance on the part of the American government; this nation is still suffering from the effects of this antipathy in contemporary society.

### **1987-1997: Congressional Action, Presidential Inaction and Domestic Progress**

The second era of the AIDS epidemic saw the emergence of critical Congressional legislation and a dramatic increase in the efforts of federal agencies such as the CDC, FDA, and NIH to confront and contain this infectious illness. At the same time, presidential leadership continued to be inarticulate at best, as President Bush maintained the legacy of his predecessor, and President Clinton, despite high hopes to the contrary, positioned AIDS near the bottom of his domestic political agenda.

HIV/AIDS may have elicited an unprecedented amount of silence from the executive branch of the US government and highlighted the indifference of many politicians, however, it also prompted bravery on the part of several policymakers who boldly developed critical pieces of legislation, both in terms of resources and ideology,

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<sup>24</sup> Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic*, in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 170.

during this period. These men and women capitalized upon the changing public image of PWA to redefine the reality of this disease for Americans and portray it as one endangering all citizens, not just homosexuals and IDUs. In order to pass pivotal pieces of legislation, bills that continue to protect PWA today, policymakers associated this disease with “innocent” populations and victims; while this further marginalized the majority of those being affected by this disease, these tactics were successful in forging coalitions and spurring government action.<sup>25</sup> By redefining this disease as a public health threat capable of affecting every citizen, these officials demanded the attention of Congress. This is evidenced by the fact that between 1981 and 1985, the period before Rock Hudson, Ryan White, and the heterosexual transmission of this disease, Congress held just nine hearings on AIDS. Between 1986 and 1990, however, this body held forty-nine hearings on the AIDS epidemic.<sup>26</sup> The fruits of Congress’ HIV/AIDS-related work is most evident in the passage of the Americans with Disabilities Act (ADA), and the Ryan White Comprehensive AIDS Resources Emergency Act (CARE), two of the single most important pieces of public health legislation to be produced by this body in the last several decades.

The Americans with Disabilities Act, signed into law on July 26, 1990, was the first piece of mainstream legislation that included protection measures for PWA. This bill, a set of anti-discrimination laws, defends individuals against the stigma associated with their various diseases and illnesses, primarily to preserve their basic civil rights.

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<sup>25</sup> Mark C. Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs* (Washington, D.C.: Georgetown University Press, 2001), 54, 60.

<sup>26</sup> Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs*, 58.

The ADA covers employment, public services, public accommodations, transportation and telecommunications. Most importantly, it protects all persons infected with HIV, symptomatic and asymptomatic, as well as those with AIDS.<sup>27</sup>

This act, while critical to the protection of PWA in America, remains in the shadow of the Ryan White CARE Act. Signed into law on April 18, 1990 this groundbreaking bill, which has since been reauthorized three times, in 1996, 2000, and 2006, was initially created to honor Ryan White and provide emergency assistance for the provision of healthcare and social services for PWA and their families in those areas disproportionately affected by this epidemic. Administered by the Health Resources and Services Administration, the Ryan White CARE Act is the conduit through which a variety of federal programs for AIDS are implemented. Today, the CARE Act is the federal government's largest HIV-specific program. It provides funding for primary medical care and general support for the uninsured and underinsured living with HIV/AIDS; more than 500,000 people receive medical care, prescription drugs, and ancillary services paid for with CARE funds each year.<sup>28</sup>

In order to gain support for the Ryan White CARE Act, legislators marketed this bill as one meant to benefit individuals like Ryan White—children and hemophiliacs who contracted this disease through no fault of their own. Though children represented just 1.7 percent of PWA during the time of these debates, they were introduced 41 percent of the time that policymakers mentioned any population.<sup>29</sup> In spite of its false

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<sup>27</sup> Chitwood, "United States," in *HIV and AIDS: A Global View*, 264.

<sup>28</sup> Institute of Medicine of the National Academies, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* (Washington, D.C.: The National Academies Press, 2005), 30.

<sup>29</sup> Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs*, 63.

advertisement, this act represents one of this disease's most significant achievements in the American political arena. The first piece of legislation adopted by Congress aimed specifically at the protection and support of those living with HIV/AIDS, the Ryan White CARE Act signaled the government's involvement with this epidemic; the funds distributed by this program have since constructed this country's HIV/AIDS health infrastructure. With an allocation of just \$875 million USD in FY 1991, this program's budget has grown tremendously; it was responsible for over \$2 billion USD in FY 2007.<sup>3031</sup>

Though the ADA and Ryan White CARE Act are two of the most important bills to be introduced during this period, they are certainly not the only ones of distinction. The Housing Opportunities for People with AIDS Act, passed in 1991, provides grants to states and localities to meet the housing needs of PWA.<sup>32</sup> Furthermore, the Health Insurance Portability and Accountability Act addresses the concerns of HIV-positive individuals over their right to privacy when changing jobs and returning to work after a period of disability, as well as attends to their fears of exclusion based on their preexisting medical conditions, their denial of insurance coverage based on their illness, and their cancellation of coverage because of the high costs of insuring someone who is HIV-positive. Additionally, there is the AIDS Drug Assistance Program, which provides expensive AIDS medications to low-income HIV-positive individuals with limited or no medical coverage, and the Harkin-Humphrey Amendment to the Civil Rights Restoration

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<sup>30</sup> Donovan, *Taking Aim: Target Populations and the Wars on AIDS and Drugs*, 60.

<sup>31</sup> The Henry J. Kaiser Family Foundation, "HIV/AIDS Policy Fact Sheet: Ryan White Comprehensive AIDS Resources Emergency Act," The Henry J. Kaiser Family Foundation, <http://www.kff.org/hiv/aids/upload/7582.pdf> (accessed March 11, 2008), 3.

<sup>32</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxvii.

Act, which protects those workers and job applicants living with HIV/AIDS against discrimination based on their condition.<sup>33</sup>

Guided in part by the portrayal of this disease as one that affects women, children, and healthcare professionals as frequently as MSM and IDUs, and in part by the population's increased knowledge of this disease, Congress was able to enact a substantial number of bills during this time. Together, these acts served to revolutionize the provision of care and support for those living with HIV/AIDS in the US.

Federal agencies were extremely active between 1987 and 1997. A product of the surge in HIV/AIDS awareness and funding from Congress, the pressure placed on them by organizations such as ACT UP, and the health crisis threatening American society, these departments took a variety of steps to slow the rapid transmission of this disease throughout the general population and address the needs and concerns of PWA. During this time, the FDA approved the first ARV agent for AIDS—AZT, and created a new class of experimental drugs known as Treatment Investigational New Drugs. This organization also accelerated the drug approval process for experimental medications and began to allow the importation of unapproved drugs for those persons living with fatal illnesses. Finally, it sanctioned the first clinical trial for an AIDS vaccination using human subjects. In the 1990s, the FDA went on to approve the use of AZT to treat pediatric AIDS, authorized an oral HIV test and HAART, as well as a viral load test, an HIV urine test, and a blood sample collection kit for anonymous testing in one's home.<sup>34</sup>

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<sup>33</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 23-24, 210.

<sup>34</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxvi.



The NIH was similarly industrious during the late 1980s and early 1990s, creating an Office of AIDS Research in 1987, restructuring its AIDS program, and establishing the AIDS Clinical Trials Group. It also endorsed the access of persons not enrolled in a clinical trial to experimental drugs.<sup>35</sup>

Most importantly, the CDC, the organization that had defined this epidemic, named its risk groups, and published safety guidelines on this disease during its initial years, increased the scope and intensity of its efforts to contain HIV/AIDS in the US. Towards this end, it issued workplace safety rules, began making public service announcements about HIV/AIDS, held a national conference on HIV and Communities of Color, and in collaboration with the WHO, declared the first World AIDS Day on December 1, 1988.<sup>36</sup>

The accomplishments listed above are only a small sample of the measures taken by these agencies and those like them to combat HIV/AIDS in the US and assist those living with it. These efforts were extremely successful, and although they came later than most PWA and HIV/AIDS activists would have preferred, they do represent a revolutionary shift in the manner in which this disease was addressed in the United States. No longer was the burden of AIDS falling solely on the shoulders of private agencies and the victims of this fatal disease. The American government, at long last, placed this disease on the domestic political agenda; it began to protect the health of its citizens.

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<sup>35</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxvi.

<sup>36</sup> *Ibid.*, xxvi-xxvii.

The leadership efforts of Congress and the ambitious endeavors undertaken by federal agencies aside, presidential leadership is critical to an issue's success on the political agenda. Presidents Bush and Clinton, however, were only slightly more interventionist than their predecessor with regards to this disease. The Bush administration's response to this epidemic was shaped by prejudice, fear, misconceptions, and silence; President Bush dedicated just one speech to HIV/AIDS during his time in office even as the number of HIV-positive individuals swelled and the number of deaths attributed to AIDS grew. In a 1991 Report of the National Commission on AIDS entitled, *America Living with AIDS*, this body criticized national leaders, and particularly Presidents Reagan and Bush, for their unwillingness to devote sufficient attention, funding, and resources to this crisis. It stated:

Our nation's leaders have not done well. In the past decade, the [Reagan/Bush] White House has rarely broken its silence on the topic of AIDS. Congress has shown leadership in developing critical legislation, but it has often failed to provide adequate funding for AIDS programs. Articulate leadership guiding Americans towards a proper response to AIDS has been notably absent.<sup>37</sup>

With the transition to a democratic White House in 1992, and the advent of the Clinton administration, many AIDS activists and PWA had high hopes for this president, who appeared much more sympathetic to the plight of PWA than those who had come before him. While Clinton did create a White House Office of National AIDS Policy and Presidential Advisory Council on HIV/AIDS, as well as a panel to accelerate drug approval processes, he gave little authority or power to National AIDS Coordinators and

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<sup>37</sup> National Commission on Acquired Immunodeficiency Syndrome, "Executive Summary," in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 175.

only rarely discussed AIDS in public.<sup>38</sup> Consequently, President Clinton was censured by his own Advisory Council in 1998, when it issued a no-confidence statement in this administration's commitment to reducing the spread of HIV/AIDS based on its ban on federal funds to support a needle exchange program.<sup>39</sup> Despite several very public overtures, President Clinton was no more predisposed to make AIDS a national priority during his first term than President Reagan or President Bush. Though both Bush and Clinton increased federal funding for HIV/AIDS-related care and support services, their disinterest in commanding a forceful national response to this disease is indicative of the fact that funding, while necessary and useful, is not always sufficient to address an item on the political agenda.

The definition of AIDS is not the only feature of this disease that has changed over time. The response of the government, and particularly Congress and a variety of federal agencies, has evolved considerably as the national mood has matured, technology has advanced, and the critical need for government resources and attention has intensified. Unfortunately, the same cannot be said of the American presidency. Though this period of domestic progress, between 1987 and 1997, witnessed both the peak and decline of HIV-incidence in the US, the introduction of HAART, and tremendous improvements in the provision of care for PWA, only a small amount of this development can be attributed to the efforts of American presidents, who remained indifferent to the struggles of PWA.

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<sup>38</sup> Feldman and Miller, *The AIDS Crisis: A Documentary History*, 179.

<sup>39</sup> Lerner and Hombs, *AIDS Crisis in America: A Reference Handbook*, 19.

## **1997-Present: Humanitarian Concern, Enlightened Self-Interest and the Internationalization of AIDS**

The contemporary era of AIDS in the United States is characterized by this disease's transition on the political agenda from a domestic health crisis to an international security threat. Accordingly, the manner in which HIV/AIDS is attended to in Washington has also changed. Domestic progress, which dominated the second political era of AIDS, has diminished. Granted, Congress has continued to enact legislation such as the Ricky Ray Hemophilia Relief Fund Act to pay hemophiliacs infected via unscreened blood-clotting agents between 1982 and 1987, reauthorized the Ryan White CARE Act three times, and approved funding for the Minority HIV/AIDS Initiative. Additionally, the introduction of a rapid HIV test and FDA approval of fusion inhibitors have also enhanced the quality of life for PWA in America. However, these contributions pale in comparison to the number of setbacks witnessed by contemporary society in combating this disease, largely due to governmental inaction.

HIV/AIDS transmission rates may have leveled off in the 1990s, but they have not been reduced since then. In some areas of the country, HIV-incidence has increased as new technology and resources have signaled the end of this epidemic for many and led to a second wave of this outbreak.<sup>4041</sup> Moreover, the number of drug-resistant strains of HIV has increased, a vaccination is not forthcoming, and this disease is increasingly affecting minority populations even as it strains this country's healthcare and insurance industries. The disparity between that which is needed, in terms of both attention and

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<sup>40</sup> Institute of Medicine of the National Academies, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, 27.

<sup>41</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxvii-xxviii.

resources, to mount an effective response to HIV/AIDS in the United States and that which is actually being provided is growing; American presidents have finally intervened in the handling of this epidemic only to shift the political focus on this disease away from domestic treatment towards international security concerns.

The roots of this transition lie in a report published by the Board on International Health of the US National Academy of Science's Institute of Medicine entitled, *America's Vital Interest in Global Health: Protecting Our People, Enhancing Our Economy, and Advancing Our International Interests*, in 1997. This evaluation, by one of this country's most respected academic institutions, maintains that an investment in global health, defined as "health difficulties, issues, and concerns that transcend national boundaries; may be influenced by circumstances or experiences in other countries; and are best addressed through cooperative actions and solutions," will increase domestic security, improve the national economy, and develop US interests abroad.<sup>42</sup>

Globalization, the information revolution, the increasing mobility of the world's population, and civil disorder are encouraging the resurgence of infectious diseases in society; these trends threaten to undermine the security of the developed and developing worlds alike, depress the purchasing power of US client states, and leave this country vulnerable to health crises and economic decline. Thus, this report argues that for reasons of humanitarian concern and enlightened self-interest, developed nations, and

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<sup>42</sup> Christopher P. Howson, Harvey V. Fineberg, and Barry R. Bloom, "The pursuit of global health: the relevance of engagement for developed countries," *The Lancet* 351, no. 9102 (1998): 586-87.

particularly the United States, should actively seek to improve health in the developing world.<sup>43</sup>

Initiated by NGOs and activists in 1997, the worldwide movement to place pressure on the Clinton administration and its counterparts in the Group of Eight to buy and donate ARVs to Third World countries further garnered attention from American politicians for HIV/AIDS.<sup>44</sup> International HIV/AIDS Conferences in Durban, South Africa and Barcelona, Spain in 2000 and 2002 respectively sustained the pressure placed on the American government by this campaign. At these meetings, the question of universal access to ARVs and concrete proposals for making these drugs more widely available were proposed as the US government, trapped by the language of human rights, and increasingly aware of the security implications of HIV/AIDS, increased aid and resource distributions to the South.<sup>45</sup>

The pressure that was placed on the Clinton administration eventually worked. The interest of the US government in the global implications of this disease became apparent during President Clinton's second term, when he ordered Sandra Thurman—Director of the Office of National AIDS Policy—to lead a fact finding delegation to sub-Saharan Africa and report back to him with recommendations for policy proposals for this region on World AIDS Day in 1998. Over the course of the next two years, aid to sub-Saharan Africa grew markedly and a new AIDS plan—the Leadership and Investment in Fighting an Epidemic Initiative—was launched in both sub-Saharan Africa

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<sup>43</sup> Howson, Fineberg, and Bloom, "The pursuit of global health: the relevance of engagement for developed countries," 586-87.

<sup>44</sup> Laurie Garrett, "The Challenge of Global Health," *Foreign Affairs* 86, no. 1 (2007): 14-38.

<sup>45</sup> James F. Keenan, "Developments in Bioethics from the Perspective of HIV/AIDS," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 419-20.

and India; it initially increased HIV/AIDS assistance to these areas by \$100 million USD.<sup>46</sup> These steps are representative of the American government's transition towards an international response to HIV/AIDS.

The year 2000 is not only indicative of the dawn of the new millennium, but of the birth of a new strategy to fight HIV/AIDS. After a CIA report declared that HIV/AIDS increased the prospects of “revolutionary wars, ethnic wars, genocide, and disruptive regime changes,” President Clinton designated HIV/AIDS a national security threat; this was the first time in history that an American president had classified a disease as such.<sup>47</sup> The designation of HIV/AIDS as a threat to national security meant it fell to the National Security Council to craft policy solutions to address this illness. As evidenced by the authorization of the Global AIDS and Tuberculosis Relief Act, this transfer resulted in the distribution of additional funds and resources to those regions most affected by HIV/AIDS.<sup>48</sup>

This classification, which places HIV/AIDS in the same category as American oil interests in the Middle East, has had profound implications for the treatment of this disease by the American government. As a threat capable of undermining political and economic stability, threatening US interests abroad, and fostering conflict, HIV/AIDS became a serious topic in Washington. As author P.W. Singer notes, “Thinking about AIDS as a security threat helps clarify how this scourge reaches beyond individual lives and deaths into the realm of violence and war—and thus strengthens the case for serious

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<sup>46</sup> Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Washington, D.C.: Georgetown University Press, 2002), 127.

<sup>47</sup> P.W. Singer, “AIDS and International Security,” *Survival* 44, no. 1 (2002): 145.

<sup>48</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 127.

action. Fighting AIDS is not just a matter of altruism, but enlightened self-interest.”<sup>49</sup> It was not until HIV/AIDS became a heterosexual disease, and thus capable of infecting the general population, that the American government took action against this disease in a domestic context. Similarly, it was not until HIV/AIDS was viewed as a menace capable of affecting this country’s national security, economic interests, and political position that the government began to intervene in the spread of this disease in an international context.

Just three months before Clinton’s announcement, the UN Security Council had also made an unprecedented move, when it gathered for the first time to debate a health issue—HIV/AIDS. Two months after Clinton’s statement, in a gesture that cannot be considered a coincidence given the position of the United States on the UN’s governing body, the Security Council adopted Resolution 1308, which highlighted the threat of this disease to international security, particularly in conflict and peacekeeping settings.<sup>50</sup> The declaration of HIV/AIDS as threat capable of destroying governing bodies and all that which constitutes the fabric of a state fortified the American government’s resolve to combat this disease and gathered support for its efforts from other states in the international arena.

The commitment of the American government and that of the international community was further strengthened by the UN General Assembly’s Special Session on HIV/AIDS in 2001. (UNGASS) From this meeting came the Declaration of

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<sup>49</sup> P.W. Singer, “AIDS and International Security,” 155.

<sup>50</sup> UNAIDS, “Fact Sheet: HIV/AIDS and Security,” UNAIDS, [http://data.unaids.org/Topics/Security/fs\\_security\\_en.pdf](http://data.unaids.org/Topics/Security/fs_security_en.pdf) (accessed March 31, 2008).



Commitment on HIV/AIDS. This document, which unites political preferences with medical goals, notes that all people, regardless of socioeconomic status, location, age, and race are susceptible to this disease. Moreover, it argues that this pandemic is a global emergency, a challenge to human rights, life and dignity, and a threat to the world's social, economic and political institutions.<sup>51</sup> UNGASS introduced targets for prevention initiatives and plans for resource and capital mobilization, and accelerated the momentum of the global movement to contain and control the proliferation of HIV/AIDS.<sup>52</sup>

In 2002, the UN established the Global Fund to Fight AIDS, Tuberculosis, and Malaria. The creation of this foundation, at a time when HIV/AIDS was the leading cause of death for both men and women ages fifteen to fifty-nine, has been supported by the US government both rhetorically and monetarily, and has reinvigorated public and political interest in this topic; this is evidenced by the increase in American media coverage since its inception.<sup>53</sup><sup>54</sup> During this same year, President George Walker Bush introduced the International Mother and Child HIV Prevention Initiative. This \$500 million dollar plan was enacted to prevent the transmission of this disease from mothers to infants as well as improve healthcare delivery in sub-Saharan Africa and the Caribbean.<sup>55</sup>

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<sup>51</sup> United Nations General Assembly, "Declaration of Commitment on HIV/AIDS: Global Crisis - Global Action," United Nations General Assembly, 26<sup>th</sup> Special Session, 2002.

<sup>52</sup> Peter Piot, "AIDS: from crisis management to sustained strategic response," *The Lancet* 368, no. 9534 (2006): 527.

<sup>53</sup> Piot, "AIDS: from crisis management to sustained strategic response," 526.

<sup>54</sup> Mollyann Brodie, Elizabeth Hamel, Lee Ann Brady, Jennifer Kates, Drew E. Altman, "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," *Columbia Journalism Review*, Supplement: March/April 2004, 2.

<sup>55</sup> Office of the Press Secretary, "Fact Sheet: President Bush's International Mother and Child HIV Prevention Initiative," The White House: President George W. Bush, <http://www.whitehouse.gov/news/releases/2002/06/20020619-1.html> (accessed April 1, 2008).

The prominent position of HIV/AIDS on the American political agenda was crystallized during President Bush's third State of the Union address on January 28, 2003, when he introduced the President's Emergency Plan for AIDS Relief. This five-year, \$15 billion dollar program focused on prevention, care, and treatment, represented the largest disease-specific health initiative ever undertaken by a nation-state. PEPFAR and other health programs, which have encompassed a large portion of the foreign aid not dedicated to Iraq by this administration, are considered to be several of the current executive's most notable accomplishments. Recently, when PEPFAR came up for reauthorization, the House Foreign Affairs Committee responded by approving a bipartisan compromise authorizing \$50 billion US dollars over the next five years to support campaigns against HIV/AIDS, tuberculosis, and malaria. If passed, this new bill will authorize between \$37 and \$41 billion USD to fight AIDS in the developing world.<sup>5657</sup> It is important to note that the recommended \$50 billion dollar budget is much larger than the \$30 billion dollar allocation originally requested by President Bush for this bill.<sup>58</sup>

The ascendancy of HIV/AIDS on the American political agenda is a consequence of its designation as a national security threat, and of the subsequent support of the American government, and especially President Bush, to this cause. Indeed, his interest has demonstrated, in a domestic context, the effect of strong presidential leadership on an issue, and particularly a health matter. The inability of Congress to reconcile the passage

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<sup>56</sup> Garrett, "The Challenge of Global Health," 14-38.

<sup>57</sup> "The Global AIDS Fight," *New York Times*, sec. A, February 29, 2008.

<sup>58</sup> "The Global AIDS Fight," sec. A.

of powerful pieces of legislation to combat HIV/AIDS with sufficient amounts of funding to effectively support them has clearly begun to dissipate; the fact that this body superseded President Bush's request for funding to fight HIV/AIDS in upcoming years is indicative of this progress.<sup>59</sup>

The evolution of the American political agenda has been extremely beneficial for the developing world, and particularly sub-Saharan Africa, where HIV/AIDS is stunting development, both in terms of life expectancies and economic growth. This region is that in which more than two out of three adults and more than nine out of ten children infected with HIV live, and where more than three out of four deaths attributed to this disease occur.<sup>60</sup><sup>61</sup> The dichotomy between the developed world, which owns all of the resources and tools necessary to mount an effective campaign against this disease, and the developing world, where there are no materials to deal with this epidemic, is real and dynamic.<sup>62</sup> In *AIDS and the Policy Struggle in the United States*, author Patricia D. Siplon contends:

Figuring out what to do about this gap may be the most important challenge worldwide for AIDS policymakers. Because the United States is the richest and most powerful country on earth, as well as the one where HIV and AIDS were first formally discovered and have been copiously researched for the past two decades, it is, by necessity, a major player in the search for policy solutions.<sup>63</sup>

The US is, based on its central role in the history of this disease and its powerful

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<sup>59</sup> National Commission on Acquired Immunodeficiency Syndrome, "Executive Summary," in *The AIDS Crisis: A Documentary History*, ed. Douglas A. Feldman and Julia Wang Miller, 175.

<sup>60</sup> Peter Piot, Michael Bartos, Peter D. Ghys, Neff Walker, and Bernhard Schwartlander, "The Global Impact of HIV/AIDS," *Nature* 410, no. 6831 (2001): 971.

<sup>61</sup> UNAIDS, "AIDS epidemic update: December 2007," UNAIDS, [http://data.unaids.org/pub/EPISlides/2007/2007\\_epiupdate\\_en.pdf](http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf) (accessed April 5, 2008), 15.

<sup>62</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 112.

<sup>63</sup> *Ibid.*, 112.

place in the contemporary international arena, in a position to lead an effective global response to HIV/AIDS. However, the question remains, how successful has it been in doing so thus far? On the one hand, since the US has taken responsibility for leading the fight against this pandemic, financing for HIV programs has grown exponentially. Between 1996 and 2005, funds dedicated to addressing HIV/AIDS in low- and middle-income countries increased twenty-eight fold, reaching \$8.3 billion USD in 2005. The rate of increase has grown most rapidly since UNGASS, with an annual average increase of \$1.7 billion USD between 2001 and 2004. Moreover, the number of individuals receiving ARVs in these states expanded rapidly between 2001 and 2006, from roughly 240,000 individuals in the beginning of this period to over 1.5 million recipients by this interval's end.<sup>64</sup>

The merits of the heightened interest of the American government in this global pandemic cannot be denied. Indeed, this third era of AIDS is indicative of this item's successful placement on both the American domestic political agenda and on the international political agenda more broadly. At the same time, although there is more funding available to this campaign than at any previous point in history, it is not clear that the American government's response to this disease in an international context has been superior to its domestic reaction.

The US may have declared HIV/AIDS a security threat and consequently improved programs to combat it worldwide, however, it has yet to encourage pharmaceutical companies to make drugs more widely accessible, work cooperatively

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<sup>64</sup> Piot, "AIDS: from crisis management to sustained strategic response," 527.

with NGOs and international agencies to coordinate initiatives and resources, or dedicate the funds necessary to launch a truly successful global attack on HIV/AIDS.<sup>65</sup> For example, the US has not donated the amount requested by the Global Fund to Fight AIDS, Tuberculosis, and Malaria, despite its consistent vocal support for this organization.<sup>66</sup> Furthermore, with regards to three major goals of AIDS foreign policy activists—debt cancellation, financial assistance, and affordable treatment, the US must still fulfill its obligations to the 6,800 persons who are infected with HIV and the 5,700 persons who die from AIDS each and everyday.<sup>67</sup> This is to say nothing of the impact of this international focus on the domestic political agenda. Even as the global implications of this disease have settled in the American consciousness, the domestic ramifications of this agenda have largely been ignored as most Americans, both in and outside of government, have come to believe this disease has been contained and reduced to a chronic illness in this country.

This era of AIDS, beginning in 1997 and stretching into the present, has witnessed both a decline in domestic concerns over this disease and a simultaneous rise in its international relevance for American policymakers. The versatility of this epidemic has been made clear as it has come to dominate the American political agenda, both domestically and internationally, and consequently, the political agendas of nation-states throughout the world. This disease has been defined, redefined, manipulated, and maneuvered and accordingly, has come to be recognized in terms of humanitarian

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<sup>65</sup> Gostin, *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*, xxiv.

<sup>66</sup> Siplon, *AIDS and the Policy Struggle in the United States*, 127. In 2001, when the Global Fund to Fight AIDS, Tuberculosis, and Malaria was launched, United Nations Secretary General Kofi Annan asked the US to donate \$2 billion dollars towards this organization; the US responded by giving \$200 million dollars.

<sup>67</sup> UNAIDS, “AIDS epidemic update: December 2007,” 4.

considerations and enlightened self-interest; this frame of reference has been critical to its political success. The poster child of the modern global health campaign, the placement of this disease on the political agenda of the US and many other nation-states has been as much a product of the current state of the international system as the health crisis at hand.

### **Federal Funding Overview: The Depth of Policymakers' Pockets**

The attitudes, language, and actions of policymakers have evolved considerably throughout the history of HIV/AIDS in the United States of America. After a period of apathy and ignorance, members of Congress rallied together to enact legislation to benefit and support PWA in the US. This phase was followed by one in which the US government, led by Presidents Clinton and Bush respectively, declared this disease a national security threat and responded by making an investment in global public health. An analysis of the trends in US federal funding for HIV/AIDS between 1981 and 2004 will place the evolution of this disease on the political agenda in perspective and allow us the opportunity to examine the relationship between the rhetoric of Washington, and the real depth of its pockets.

Between 1981 and 2004, the US government allocated approximately \$150 billion USD for domestic and international HIV/AIDS programs. Subsequent to the discovery of this disease in 1981, the US government allocated several hundred thousand dollars to federal agencies to study this disease. That amount increased to \$8 million USD one year later, and nearly doubled each year thereafter until 1989. Although increases in funding have been far more gradual since that period, aid has been forthcoming, with the US

allocating \$18.5 billion USD towards HIV/AIDS activities in 2004.<sup>68</sup> Moreover, it is important to note that spending patterns have since accelerated.

Federal funding for HIV/AIDS, which includes both mandatory and discretionary allocations, can be divided into the following categories: care, or health and support services; cash and housing assistance; research; prevention; global or international programs.<sup>69</sup> The lines between these divisions are rarely distinct. For the first fifteen years after the birth of this epidemic in the US, these programs were largely supported by discretionary funds, which are allocated by Congress. However, by 1995, mandatory funding, which falls to Medicaid, Medicare, Social Security, and other US healthcare financing programs to distribute, equaled discretionary funding and has since surpassed it. This acceleration is largely due to the long gestation period for AIDS, which debilitates and cripples the human body over the course of many years, thus predisposing victims of this disease to qualify for programs for low-income and disabled individuals. Likewise, many of those who acquire this disease in the US come from marginalized communities and are more likely to be enrolled in these programs already. Nevertheless, both mandatory and discretionary funds have increased, reflecting a growth in the number of people living with this disease, as well as a rise in costs for providing for them.<sup>70</sup>

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<sup>68</sup> Todd Summers and Jennifer Kates, “Trends in U.S. Government Funding for HIV/AIDS: Fiscal Years 1981 to 2004,” The Henry J. Kaiser Family Foundation, March 2004, 1-4.

<sup>69</sup> Summers and Kates, “Trends in U.S. Government Funding for HIV/AIDS: Fiscal Years 1981 to 2004,” 1.

<sup>70</sup> Summers and Kates, “Trends in U.S. Government Funding for HIV/AIDS: Fiscal Years 1981 to 2004,” 1-4.

In 2004, domestic programs accounted for nearly 90 percent of the US government's HIV/AIDS budget. However, funding for international initiatives dedicated to addressing this disease, which began increasing between 2001 and 2004, has continued to grow rapidly.<sup>71</sup> The culmination of this expansion, which demonstrates the shifting priorities of the American government, is the \$50 billion dollar budget for PEPFAR and similar activities put forth by the House Foreign Affairs Committee this year.

The US government has responded to the HIV/AIDS pandemic in an unprecedented manner; never before has it showered a health issue with so much attention and resources. Nonetheless, with spending on HIV/AIDS totaling less than 1 percent of the American government's \$2.3 trillion dollar budget in FY 2004, and having increased but modestly in overall expenditures since then, it remains a point of contention whether the rhetoric of policymakers can be reconciled with the reality of their actions.<sup>72</sup>

### **Implications of the Politicization of HIV/AIDS**

The politicization of HIV/AIDS has been an arduous process, but a successful one. This disease, initially ignored by politicians, was placed on the political agenda as a result of the efforts of dedicated legislators and activists, the influence of HIV-positive celebrities and public personalities, and most importantly, by the designation of this disease as one capable of threatening mainstream America. By redefining HIV/AIDS, politicians were able to place this disease in a conventional context, elicit funds to be dedicated towards it,

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<sup>71</sup> Ibid., 2.

<sup>72</sup> Ibid., 4.



and make it a priority on the domestic political agenda. Similarly, the internationalization of HIV/AIDS required the reframing of this disease as a national security threat. It was this classification that garnered the long desired attention of the American president, and generated global interest in this pandemic. Subsequent to the designation of this disease as a security threat, it became a foreign policy issue as well as a domestic matter in America, and with the support of this state, was placed on the political agendas of countries throughout the world. The politicization of HIV/AIDS has been critical to its position as the leader of the global public health movement.

HIV/AIDS is a devastating illness, and is unique in terms of its timing and impact in contemporary society. Nevertheless, it is not the only health crisis affecting the world today. The steps taken to place this disease on both the public and political agendas in the United States, and consequently, those in many other parts of the world, are not distinctive in content, despite how remarkable they are in character, and thus, they can be replicated. These processes, which were so successful in promoting the interests of PWA, can be repeated; they can be used to advance the concerns of other groups, or in this case, humanity at large. In the following chapter, I will look to the positioning of HIV/AIDS on the American public and political agendas in order to invigorate interest in horizontal, broad-based initiatives, reset these agendas, and launch a new, more inclusive global health movement.

## **CHAPTER SIX: CONCLUSION**

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### **Resetting the Agenda: A Sustainable System for Global Public Health**

Public health is of critical importance in the world today. This issue is unique in that it is essential to the welfare of every state, regardless of its wealth, power, and status in the international system. As people, our health and well-being is requisite to the exercise of our humanity, and accordingly, it is a link that connects individuals throughout the world. Nevertheless, it appears the bonds of our humanity have been broken; the deleterious relationship between health and wealth is demonstrative of this phenomenon. Indeed, the developing world has been devastated by the absence of resources to provide for the basic health of its citizenry, even as industrialized states have advanced far beyond the provision of fundamental healthcare to offer advanced cosmetic surgeries, ridiculing those who cannot even afford basic vaccinations for their children. As a result, the political and economic power of states in the global South has suffered alongside the people living in these countries.

Global health is generating more attention and funding than ever before in history. Given these resources, an effective campaign to improve the health of the world's poor can be mounted; change can be realized in our lifetime. If these funds are managed properly and directed towards broad-based, comprehensive programs that train community healthcare workers, construct clinics, provide medications and vaccinations, and establish safe water points, they will ameliorate the health of millions of individuals in the developing world. Currently, the vast majority of public health initiatives in the global South are characterized as disease-specific programs. While generous and

necessary, vertical approaches to improving global health are not the most efficient ways to affect change. These programs must be integrated into horizontal initiatives. We must encourage the construction of sustainable health infrastructures in the developing world and guarantee the health and development of future generations, even as we attend to the diseases and ailments of the present one. If we do not, these states will continue to wait in a purgatory of economic stagnation, political disorder, and cultural devastation. The developing world will remain trapped in a cycle of poverty, subject to the tyranny of the short-term, as its most valuable asset—its people, remain incapacitated by those illnesses that are not only treatable, but also preventable.

Comprehensive programming can be positioned in the minds of Americans and their political representatives. Agenda-setting and policy formation, the primary conduits through which change is realized in this country, will be critical to this placement, and the shift away from disease-specific support towards a more inclusive approach to confronting the challenges of global health in contemporary society.

The positioning of HIV/AIDS on the American public and political agendas is the ultimate manifestation of agenda-setting and policy formation tactics in action. The lessons learned from the history of this disease, which was transformed from an issue that was avoided by the public and policymakers alike, to the most recognized health concern of our time, are truly informative, and representative of that which can be accomplished by dedicated individuals, popular support, and proactive strategies. The history of this disease has taught us that the public and political agendas must be addressed separately; in this way, they are both more accessible and more readily transformed. The rise of

HIV/AIDS to the public agenda suggests that health initiatives are most likely to succeed when propagated by activists, celebrities, and the media, while the political agenda requires public attention, broad-based framing which appeals to the enlightened self-interest and humanitarian concerns of the population, and strong Congressional and presidential leadership.

The need to contain the HIV/AIDS pandemic in the developing world is undeniable given its devastating effects on the populations of these states. This is a disease that must be addressed without delay. At the same time, however, singular support for this disease will not strengthen the capacities of countries in the global South, nor will it save their failing public health infrastructures whose inadequacies gave rise to the rapid transmission of this disease in the first place. We must lay the foundation for sustainable development in these states by promoting initiatives that seek to provide for the total health of these populations, not just those who are affected by HIV/AIDS. There is no better way to accomplish this than by analyzing the efforts of those men and women who placed this disease on the public and political agendas of the most powerful country in the world, and transposing their strategies onto the global public health campaign.

### **Transposing Tactics, Transforming Lives, and Changing the World**

No problem becomes an issue on its own, but is manufactured by the men and women who creatively and competently mold it into one. By studying the example set by HIV/AIDS activists, which includes members of the public as well as policymakers who actively sought to address this pandemic, we can adopt their successful strategies and

position general health on the public and political agendas, thus transforming the global health movement and the lives of men and women throughout the developing world.

Mobilizing public interest in an issue is invaluable. The HIV/AIDS campaign demonstrates the importance of garnering the attention of this audience; it is not only necessary for educational purposes, but to encourage government action and elicit national resources. Cohesive groups of creative activists, emphasizing direct action and self-empowerment, are crucial to the placement of international general health on the public agenda. Like those groups who organized on behalf of AIDS, individuals supporting public health more broadly must utilize a variety of tactics, ranging from conservative letter-writing and lobbying efforts, to nonviolent political action and civil disobedience. In doing so, activists will engage the public, generate awareness, pressure the government, and challenge the status quo.

Likewise, celebrity support will be critical to the positioning of general health and horizontal initiatives on the public agenda. American citizens identify with famous individuals, who have the power to bring this issue to the attention of the public, and structure the consciousness of these men and women. Celebrities make issues more visible and accessible to the public, who are able to relate to these concerns vis-à-vis their favorite stars. What Rock Hudson, Ryan White, and Magic Johnson did for HIV/AIDS, Scarlett Johansson, Paul Farmer, and Barack Obama can do for global public health.

The efforts of those advocating on behalf of this issue, both civilians and celebrities, will need to be covered by the media if global public health is going to be placed on the political agenda, and particularly if its significance is going to supercede that of

HIV/AIDS. The media is the central channel through which information is disseminated in American society. This outlet both structures and reflects national opinion, and is critical to making information about this agenda item available to every citizen. Indeed, the media facilitates the popularization of an issue and thus, its endorsement will play a central role in the successful positioning of international health on the agenda of the American public.

The sponsorship of an issue by the American people is necessary to place an item on the political agenda of this state and ensure that it is addressed by policymakers. Like any other item vying for a spot on this list, global public health will need to garner the support of several dedicated policymakers who will champion this cause in Congress. These legislators will need to frame this issue in such a way that it appeals to American constituents, and thus, their colleagues in Washington. One way in which this can be achieved is by redefining this issue as primarily threatening inoffensive populations—particularly women and children in the developing world, or, as proved to be extremely effective in the case of HIV/AIDS, as a threat to national security. The contemporary political climate is extremely conducive to items framed in this light. Once an issue is named a national security threat, it is quickly armed with funding, resources, and an action plan. Moreover, doing so has proven effective at seizing the attention of the president, whose leadership is essential to the success of any item on the political agenda of the United States. That said, proponents of global public health in Washington should actively seek to have this problem placed alongside HIV/AIDS as a health crisis whose devastating effects in the developing world are likely to affect this country given the

efficacy of globalization and its implications for the movement of both individuals and larger populations.

The use of these tactics, whose effectiveness has already been proven by the HIV/AIDS campaign, will be sufficient to place general health on both the American public and political agendas. By rallying the support, funding, and resources of the world's hegemonic power, an international movement will commence. Industrialized states throughout the world will respond to this positioning by realigning their own policies with those of the state that dominates the international system. Consequently, the transformative change in international health that we have been seeking since the distortion of the goals put forth at Alma Ata will take place, and men and women in the developing world will finally have the healthcare necessary to support themselves, their families, and their politico-economic systems.

### **Into the Homes of Americans, the Hallways of Washington, and the Heart of the Developing World: The Revolution of Global Public Health**

The global public health movement is not the same as the campaign that transformed HIV/AIDS into the most recognized health crisis of our time. Likewise, the struggle of the former onto both the public and political agendas in America will be very different. However, those promoting public health more generally can utilize the strategies applied by AIDS activists. In many ways, HIV/AIDS has done a great service to the international general health campaign by laying the foundation from which this movement can build momentum and revolutionize the provision of healthcare in the developing world.

The manner in which the funds available to the global health movement are spent is critical to the futures of millions of men and women in the South. These resources must go beyond treating the ailments of these populations in the present, to construct sustainable health infrastructures that will provide for these men and women for decades to come, and enhance their prospects for development. For too long, we have narrowly focused these funds on specific diseases, and in doing so, we have failed to facilitate the ability of developing states to care for their own citizens. Whether we are sponsoring health initiatives for reasons of humanitarian concern or enlightened self-interest is, in many ways, irrelevant. The health of the men and women who are suffering from maternal and child illnesses, preventable diseases, and yes, HIV/AIDS are what matters. The best way to ensure their well-being is to set aside donor preferences and make long-term investments that will save lives.

The debate between horizontal and vertical initiatives is a critical one, whose outcome will determine the fates of individuals throughout the world. Horizontal initiatives not only promote sustainability and encourage the participation of the men and women these measures are affecting, but create health infrastructures within which vertical programs will be far more successful and stable. The global public health campaign does not seek to eliminate disease-specific programs, but rather, integrate them into broader health systems. The time to position this movement on the public and political agendas is now. The global public health campaign must be brought into the homes of Americans and the hallways of Washington, and thus, redefine the reality of the everyday struggles of men and women throughout the developing world.



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